



Justice, care and personal assistance

Bridget Anderson

Document Identifier

5.3

Version

3.0

Date Due

27 May, 2020

Submission date

19 May, 2020

WorkPackage

WP5 Justice as lived experience

Lead Beneficiary

University of Bristol



**Funded by the Horizon 2020
Framework Programme of the European Union**

Acknowledgments

I would like to thank the research participants and authors of the national reports for providing the empirical material that informs this Deliverable, and reviewers Dorota Lepianka, Eva Kittay, and Pier-Luc Dupont for their careful reading.

This publication has been produced with the financial support of the Horizon 2020 Framework Programme of the European Union. The contents of this publication are the sole responsibility of the authors and can in no way be taken to reflect the views of the European Commission.

Copyright © 2020, ETHOS consortium – All rights reserved ETHOS project

The ETHOS project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 727112

Change log

Version	Date	Amended by	Changes	Reviewers
1	15 November 2018	Bridget Anderson		
2	19 December 2018	Bridget Anderson	<p>Strengthened the theoretical discussion including the applicability of capability to disability studies</p> <p>Added detail to the methodology</p> <p>Included additional empirical findings</p> <p>Integrated theory and findings more carefully</p>	<p>Dorota Lepianka</p> <p>Eva Kittay</p>
3	29 October 2019	Bridget Anderson	<p>Inserted additional material on gender, ethnicity and migration on p. 9 – 10; p.21; p. 25-56; p. 30.</p> <p>Added case study guidelines as an appendix.</p> <p>Stated aims of recommendations.</p> <p>Amended abstract</p>	<p>Following comments from the Commission reviewers</p>
4	27 April 2020	Bridget Anderson	<p>Introduction describes how the Deliverable is related to the task as described in the DoW. Inserted paragraph explaining limited attention to ethnicity/migration on p.1; expansion of literature review;</p>	

			<p>inserted references to methodological note accompanying national case studies at various points in the text but particularly in Section 3; inserted additional material on gender pages 12-17. re-writing section 5 with greater attention to gender; gender integrated into discussions on time and mobility; additional material in conclusion on gender.</p> <p>Added appendices 1. Case study protocol; 2. Methodological notes; 3. Researcher training agenda; 4. Suggested interview schedules.</p>	
--	--	--	---	--

Partners involved

Partner No.	Partner Name	People involved
4	University of Bristol	Bridget Anderson
2	ETC-Graz	Isabella Meier
3	Central European University	Judit Veres

1	Utrecht University	Trudie Knijn Jing Hiah
6	University of Coimbra	Laura Brito
5	Bogazici University	Basak Akkan Simla Serim

Executive Summary

ETHOS work package 5 is concerned with justice as lived experience. It examines the subjective experiences of those vulnerable to injustice. Deliverable 5.3 draws on and seeks 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. It explores the effects on capabilities and functionings of everyday practices of recognition and redistribution in private homes with specific regard to the lives of adult physically disabled care users and the people who are paid to provide them with care. Thus, it covers those perceived as potentially vulnerable and therefore eligible for provision but also care workers/personal assistants who provide services and are often in low waged and precarious work.

Even setting aside debates on the relation between the normative and the empirical, focusing on care provision for disabled people in private households is a provocative starting point for European theories of justice. This focus foregrounds the gendering of social justice by touching on unpaid work in the home, how paid work is itself gendered, and the welfare state. The paper engages with the challenge of building theory from the bottom up and with non-ideal philosophical methods. It draws on mini-ethnographies conducted in five countries: Austria, Hungary, the Netherlands, Portugal and Turkey. The study originally intended to have ethnicity as a focus, specifically an engagement with migrant care workers. However, with the exception of Turkey, it proved very difficult to find migrant care workers within the tight timeframe of the project – for further explanation see Methodological Notes 5.3. Of course, ‘white’ workers too are an ethnic group, indeed it is a privilege of whiteness that it can be invisibilised as a racial category, passing unremarked, but to focus on whiteness (rather than migrant status) would have required its own in depth research project - operationalising and comparing whiteness across different European contexts would be fascinating work, but out of the scope of the ETHOS project.

The paper begins with an outline of the Capability Approach and Capability Theory and their relevance to disability before briefly outlining the methodology and national contexts. In keeping with the ‘bottom up’ approach and responding to the diversity of the case studies both within and between national reports, we then take two very different examples of elder care and disability assistance and consider what can be learned about Capability Theory from the contrasts between them. Taking these as our starting points highlights two under-explored aspects of care and capabilities: matters of independence versus connection and issues related to temporalities and process. We therefore explore these further drawing on all the national case studies.

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. This is a question that, correctly and sensitively put, most people have the possibility of engaging with. It is also a question which will produce widely variant answers depending on the personal, social and institutional situation of the person one is asking. This raises the issue of how 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. These are highly gendered, and in some cases, such as Turkey, also create networks of affiliation across borders. At the same time, the ethnographies suggest the limitations of taking Nussbaum's starting point of the separated individual who must be connected. Indeed, the personal assistance model in Austria indicates that the idealised autonomous and independent individual – in other words, disconnection - is in some cases the desired end point. Furthermore, affiliation requires someone to affiliate to. This can be experienced as a demand or trade-off, as fulfilling one person's desire for connection may require another to devote time and effort to the creation and maintenance of interpersonal emotions. However it may also enable genuinely affiliative responses, particularly over time.

Recommendations

- Bring together the theoretical, policy and practical insights gained from the experience of those who are disabled throughout their lives and those who become disabled later in life.
- Policymakers, civil society organisations and other stakeholders should clarify the meaning of 'independence' as an aim to be pursued in relation to family members, friends and local community. They should also acknowledge and problematise the gendered nature of 'family support', care work and personal assistance.
- Resources should be deployed to recognise the capacity of care users to be caregivers in practice.
- By default, disabled people should continue to receive the services they have always received as they reach retirement age. There should be studies on how these services are framed and modelled when delivered to older people.
- Participation, representation and deliberation are important in guiding people's orientation to their social environment and their responses to felt injustices. People should be educated in how these differ from and relate to each other, and the role of institutions and officials in relation to each.
- Develop responses to 'moral distress' that go beyond the expectation that individual healthcare assistants or care workers must always simply manage it. Provide care workers with ethical training.
- There should be a limitation on the number of times temporary contracts (e.g. service vouchers, zero-hour contracts) can be renewed and still be classed as 'temporary'.

Table of Contents

<i>Acknowledgments</i>	<i>i</i>
<i>Executive Summary</i>	<i>v</i>
<i>Table of Contents</i>	<i>viii</i>
<i>List of Abbreviations</i>	<i>ix</i>
<i>Table of Figures</i>	<i>x</i>
1) <i>Introduction</i>	1
2) <i>Capability Approach/Theory</i>	3
3) <i>Methodology and national contexts</i>	8
4) <i>A tale of two service users</i>	12
Antonio	13
Case study 2 ('CS')	15
5) <i>Capability, Independence and Connection</i>	19
6) <i>Capabilities, Temporalities and Process</i>	29
Time	29
Mobility	31
7) <i>Conclusion: Capability, Redistribution, Recognition, Representation</i>	33
<i>Bibliography</i>	38
<i>Appendix One: D5.3 Case Study Protocol</i>	40
<i>Appendix Two: Methodological Note to Accompany National Case Studies</i>	48
<i>Appendix Three: Training for Researchers for D5.3 national case studies</i>	61
<i>Appendix Four: Suggested interview schedules</i>	64

List of Abbreviations

CA	Capability Approach
ILM	Independent Living Movement

Table of Figures

Table 1 – Ethnographic participants by country (page 10)

1) Introduction

ETHOS work package 5 is concerned with justice as lived experience. It examines the subjective experiences of those vulnerable to injustice. The task of Deliverable 5.3 was to ‘prepare report on competing claims for justice and everyday practices of recognition and redistribution in the private household and reflect on how those tensions affects the capabilities and functioning of the various individuals/groups studied’. The Task description is: ‘Mapping of everyday negotiations of conflicting claims for justice with attention to the role of gender and ethnicity. The study will explore the accommodation of justice claims in the lives of care users and – mainly female – care workers with focus on their capabilities and functionings. This will be done by means of mini-ethnographies of five commodified care relationships, where disabled care users employ carers in private households. These will be supplemented by in-depth interviews to examine the experiences of (in)justice by care users, care workers and close relatives, paying attention to conflicts, the impact of gender, religion and race on the relationship and how disabled people and care workers understand and manage competing claims for justice.’, (DoA, p. 31-32).

We therefore 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. It explores the effects on capabilities and functionings of everyday practices of recognition and redistribution in private homes with specific regard to the lives of adult physically disabled care users and the people who are paid to provide them with care. Thus, it covers those perceived as potentially vulnerable and therefore eligible for provision but also care workers/personal assistants who provide services and are often in low waged and precarious work. Even setting aside debates on the relation between the normative and the empirical, focusing on care provision for disabled people in private households is a provocative starting point for European theories of justice. This focus foregrounds the gendering of social justice by touching on unpaid work in the home, how paid work is itself gendered, and the welfare state. The paper engages with the challenge of building theory from the bottom up and with non-ideal philosophical methods (Rippon et al., 2018; van den Brink et al., 2018).

This paper draws on mini-ethnographies conducted in five countries: Austria, Hungary, the Netherlands, Portugal and Turkey. The study originally intended to have ethnicity as a focus, specifically an engagement with migrant care workers. Capability Approaches are well suited to analyse migration, as migration status is a key factor determining the conversion of resources into outcomes (see below for an explanation of terms). However, with the exception of Turkey, it proved very difficult to find migrant care workers (see Methodological Notes 5.3). This was in largely because of time pressure and the potential intrusiveness of the ethnographic method. Furthermore, it became apparent that migrant care workers are relatively unusual employed in home care provision in the Netherlands and Portugal, and do not participate in the arrangement for personal assistance for disabled persons in Austria. In Hungary and the Netherlands migrant care workers and their organisations were hesitant to co-operate and the timeframe of the project meant there was no time for longer negotiation. Notably the exception was Turkey, where many migrant workers are taking care of elderly persons (due to the specific cash-for-care arrangement in Turkey) and where the researcher has a long-term engagement with the topic. Of course, ‘white’ care workers too are an ethnic group, indeed it is a privilege of whiteness that it can be invisibilised as a racial category, passing unremarked, but to focus on whiteness (rather than migrant status) would have required its own

in depth research project - operationalising and comparing whiteness across different European contexts would be fascinating work, but out of the scope of the ETHOS project.

The paper begins with an outline of the Capability Approach and Capability Theory and their relevance to disability before briefly outlining the methodology and national contexts. In keeping with the ‘bottom up’ approach and the ethnographic method, which of its nature captures the diversity of the case studies both within and between national reports, we then take two very different examples of elder care and disability assistance and consider what can be learned about Capability Theory from the contrasts between them. Taking these as our starting points highlights two under-explored aspects of care and capabilities: matters of independence versus connection and issues related to temporalities and process. We therefore explore what the national case studies reveal about these general themes.

There are a range of different terms used by research participants to describe the support services provided to older and disabled people but these can be broadly typologised as those associated with ‘personal assistance’ and those associated with ‘care’. The literature and services associated with older people tend to use the language of ‘care’ and ‘care users’ while those associated with disabled people prefer ‘personal assistants’ and ‘service users’. The distinction is not merely terminological and signals distinct philosophical approaches to these services as will be discussed in this report. The Austrian policy described in the national study has been strongly influenced by the Independent Living Movement (ILM) which rejected the language of care as subordinating and demeaning, and prized self-determination and autonomy.¹ Shaped in part by feminist and anti-racist struggles it draws on the social model of disability that sees societies as ‘disabling’ and producing ‘disability’ in their lack of accommodation for human difference (van den Brink et al., 2018: 12). Protesting at infantilisation and objectification and rejecting the paternalism of able-bodied professionals, the ILM demands a self-determined life for disabled people and tools to enable them to control their own lives and support systems.² ‘Nothing about us without us’ is its rallying cry.

The ILM’s understanding of ‘care’ is very different from that which underlies long-term care for the elderly. There the focus is on the relationship between care worker and care user, attentiveness and personalisation. Independence is also prized by this sector, but it is more associated with ‘ageing in place’ and delaying institutionalisation which is generally considered more impersonal and restrictive than home based care (Knijn and Hiah 2018: 48). Notably there has been very little cross-fertilisation between the policy and conceptual work of disability studies on the one hand and long-term elder care on the other. The boundary between ageing with disability and ageing into disability is very fuzzy experientially, but there can be sharp distinctions in welfare policy as a result of group-based silo-isation. For example, some states withdraw disability support from people when they reach retirement age, ‘handing them over’ to older people’s services that typically do not provide the same level or kind of support as disability services.

¹ Policy explicitly states: ‘Inclusion and maximum self-determination of the lives of persons with disabilities shall be achieved through the personal budget’ (Meier, 2018: 8).

² Consider for example the following exchange between Barbara, a nurse, and Adrienne, a disabled older person: ‘Barbara argues that what you should do is change the temperature of the water from hot to cold [...] That would be good for the blood circulation. Adrienne says she agrees. Barbara reacts cheekily but with a smile: ‘It doesn’t matter whether you agree. I am saying that it is beneficial to your blood circulation’ (Knijn and Hiah 2018: 31).

We are also aware that, even within the care literature, there are issues around the term ‘care user’. Firstly, it suggests a dichotomy – as if care users could not give care, and care workers were not also receiving care – and this obfuscates a shared interest in good care. Secondly, ‘user’ suggests an instrumentalism that is often absent in practice. However, we choose the form ‘care user’ as more active than ‘care recipient’ and ‘care worker’ as an indication of the fact that the relationship is (partially) commodified. When discussing personal assistance and care work together we use the term ‘support’ and ‘support services’.

2) Capability Approach/Theory

The Capability Approach (CA), first developed by economist and philosopher Amartya Sen, is firmly within the liberal tradition, but is critical of both utilitarianism and Rawlsian thinking (Sen, 1985, 1999). Distribution alone, Sen argues, is not enough, as what matters is how distribution affects well-being: ‘The capability approach is about everyone becoming more able to do and become’ (Hughes, 2010, cited in Norwich, 2014). The focus of CA is on a person’s real freedom to achieve outcomes or ‘beings and doings’ that they value. It emerged from thinking about global development but has been promoted as a major contribution for moral evaluation more generally. It takes the capability to achieve ‘the kind of lives we have reason to value’ as its central concern. Sen began from his observation that when evaluating well-being and the quality of life that people can attain, looking only at resources – e.g. Rawls’ primary goods - is not sufficient, because people differ in their ability to convert resources (goods, services and other resources to which they have access) into outcomes. Each person has a unique profile of ‘conversion factors’ that enable them to convert resources into sets of possibilities or ‘capability sets’ that offer opportunities to achieve ‘functionings’ or the beings and doings that are living a life that one has good reason to value. These conversion factors are personal/individual, social and environmental. In this way CA recognises the normative significance of individual and social diversity. Depending on the circumstances a variable can be an individual characteristic, a capability or a functioning: education can be a personal characteristic, a capability or a functioning for example. Sen’s work is foundational to an important shift in development studies when it comes to dealing with inequality and poverty by moving attention not only to inequalities of income but also to inequalities of substantive freedoms to live in the world as one chooses, in this way overcoming the debates on absolute and relative poverty.

Sen’s effort to move beyond purely redistributive approaches to moral evaluation is similar to Fraser’s. Like CA Fraser criticises theories of distributive justice which ignore diversity and thereby the injustices of misrecognition. These theories cannot account for what she would describe as the politics of recognition. However, she includes Sen in this critique, an inclusion that Robeyns has argued overlooks important differences between distributive justice theorists, and particularly between Sen on the one hand and Rawls, Dworkin and Van Parijs on the other (Robeyns, 2003). Robeyns argues that Sen can accommodate recognition which is embedded in a starting point that foregrounds human difference. CA has been found particularly useful for example in relation to gender and social justice, sex, public policies, discrimination and social hierarchies, all of which have impacts on individuals’ capability sets. Robeyns goes so far as to argue that there are some issues of misrecognition that the Capability Approach

finds easier to accommodate than Fraser's overarching concept of 'participatory parity'.³ Sen, she says, starts from a position of human diversity, whereas Fraser starts from the position of a normal person: '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: 549).

In this way we can see that centralising disability can be an important challenge to theorists. Indeed, in his early critique of Rawls, Sen specifically uses the example of disability to argue that Rawls' starting point of people equally able to contribute to society does not take human diversity seriously enough, and his work has many references to disability. Furthermore, the language of 'well-being' suggests mental and social, but also physical, 'at ease-ness', foregrounding a relation between embodiment and non-material states. It is not surprising therefore that there has been considerable interest in the Capability Approach in disability studies (e.g. Mitra, 2006; Norwich, 2014; Terzi, 2005; Trani and Bakhshi, 2008; Trani et al., 2011). Scholars and practitioners are interested in how Capability Approaches to disability can facilitate a useful analytical distinction between disability and individual factors (particular impairment, race, gender etc), disability and resources (wealth, income, family networks), and disability and politico-socio-economic context (Mitra, 2006), linking individual characteristics (and how they impact on the conversion factors that transform resources into capabilities) to wider socio-economic factors. In other words, it enables an analysis of disability that is relational and situated (Terzi, 2010).

While the attraction of the Capability Approach contra Rawls is that it accounts for human differences, including embodied differences, and claims not to start from individuals who are abstractedly equal, it does have its own account of human sameness. For what is a life that one has 'good reason to value'? Why is it not simply a life that you yourself value? Sen wishes to accommodate different ideas of the good life in line with liberal philosophical thinking, hence the focus on capabilities rather than outcomes. However, he considers subjective well-being an inadequate measure of the good life because people may adapt to restrictive (social) conditions and limit their expectations – the phenomenon of 'adaptive preferences'. A person may adjust to poor eyesight because they have never dreamed of the opportunity to have spectacles, but an observer might reasonably claim that the opportunity to wear spectacles would make a significant improvement to their 'beings and doings'.

Conversely a person may find it impossible to adjust to a life without a butler because they have never met anybody who does not have one nor themselves lived without one. Indeed, it is possible to imagine a world where both people are satisfied, one with no spectacles, the other with a butler, but this is not a just world, if one person's lack of resources is related to another person's surplus. Importantly it raises the question of who is the observer who can determine the objective circumstances that are limiting one's expectations of a good life? How can this be free of particularistic cultural expectations? This is an obvious concern in matters of disability and frail old age. As many in the disability movements have argued, the lives of disabled people have often been treated as a burden to others and of no value at all, so the observer who decides that a disabled person has 'good reason to value' their lives may smuggle in able-ist assumptions. For example, the Dutch case study describes the situation of Adrienne who has a prosthetic leg. She finds it uncomfortable and is reluctant to wear it, but feels she ought to, and there is

³ According to participatory parity just social arrangements must 'permit all (adult) members of society to interact with one another as peers.'

an expectation by her doctors that she will do so. The prosthesis is a resource at her disposal, but one that she feels pressured rather than liberated by, conscious of the wider context which values an able-bodied (or able-bodied looking) life. The care workers were sympathetic and urged her to resist the pressure to conform to this ideal:

If this is enough for her, who am I then, or who is a doctor to say, you must be able to walk a particular number of miles? Sometimes things are also good as they are [...] She does not seem to be bothered by not wearing the leg [...] For whom is that (the leg)? [...] It is good to say something to her, that she also has to stay true to herself, that she shouldn't always do what others expect from her.

(Knijn and Hiah, 2018: 40-41)

For Sen the key aspect of a capability is agency or the functioning that is chosen (Robeyns, 2003; Norwich, 2014), and he is reluctant to engage with more general questions about general entitlements in a life one has reason to value. He prefers to advocate for a deliberative approach and argue for public reasoning that allows people to scrutinise and reevaluate what they have reason to value. This 'differs both (i) from trying to justify the ethics of human rights in terms of shared – and already established – universal values [...] and (ii) from abdicating any claim of adherence to universal values [...] in favor of a particular political conception that is suitable to the contemporary world' (Sen, 2004: 321).

Sen's work is deliberately under-theorised and described as Capability Approach rather than Capability Theory. Nevertheless, a number of theorists have sought to use the Capability Approach as the basis for more normative theorising. One of the most influential has been Martha Nussbaum who has used it to develop a partial theory of justice and directly engage with the question of cultural universalism.

Once we begin asking how people are actually functioning, we cannot avoid focusing on some components of lives and not others, some abilities to act and not others, seeing some capabilities and functions as more central, more at the core of human life, than others. We cannot avoid having an account, even if a partial and highly general account, of what functions of the human being are most worth the care and attention of public planning the world over.

(Nussbaum, 2010: 306)

Her response to this dilemma is to propose a list, derived from her empirical research in India, of functions that are central for human life to exceed survival as a human or 'bare humanness':

We want to describe a life in which the dignity of the human being is not violated by hunger or fear or the absence of opportunity. (The idea is very much Marx's idea, when he used an Aristotelian notion of functioning to describe the difference between a merely animal use of one's faculties and a 'truly human one'.)

(Nussbaum, 2010: 310)

Her list of ten 'central human functional capabilities' (which she argues is open ended and subject to change) attempts to specify this basic notion of the good in terms of public policy goals. Primary moral importance rests with the freedom to achieve well-being, and this freedom is to be understood in terms of capabilities. The list includes bodily health, but importantly also more relational capabilities such as emotional well-being, affiliation

and interaction, and practical reason.⁴ She argues that governments should assist in developing capabilities, and effectively her list is one of guiding political principles that should underpin a just constitution. These are ‘central constitutional principles that citizens have a right to demand from their government’ (Nussbaum, 2003). This is not a duty to promote functionings or actual beings and doings as it is for the citizen to decide how to take advantage of their capability sets. Sen refused to endorse this list – ‘pure theory cannot “freeze” a list of capabilities for all societies for all time to come, irrespective of what the citizens come to understand and value’ (Sen, 2004: 78).

Like Sen, Nussbaum distinguishes between advanced capabilities and those capabilities associated with basic needs – ‘basic capabilities’. However, for Sen this term describes what is necessary for survival and to avoid serious deprivations. The concept is useful ‘not so much in ranking living standards, but in deciding on a cut-off point for the purpose of assessing poverty and deprivation’ (Sen, 1987: 109). Nussbaum rather uses the term to refer to ‘the innate equipment of individuals that is the necessary basis for developing the more advanced capability’ (Nussbaum, 2010: 313). She gives the example of practical reason and imagination, which most newborns have, but cannot exercise without development and education (Nussbaum, 2010: 313). She distinguishes these from ‘combined capabilities’ understood as ‘internal (individualised) capabilities combined with suitable external conditions for the exercise of the function’ (Nussbaum, 2010: 313). Relevant functionings include the basic functionings of good physical health, being able to be mobile and physically present in spaces where one wants to go, as well as more sophisticated ‘beings and doings’ like having self-respect, contributing to the wider community and so on. She argues that societies should move beyond the threshold of basic capabilities but notes that inequalities also can count as capability failures. For example, racial inequalities can undermine self-respect and emotional development.

Nussbaum lists ‘control over one’s political environment’ as one of the central functions, including in this ‘being able to participate effectively in political choices that govern one’s life; having the rights of political participation, free speech, and freedom of association’ (Nussbaum 2003: 311). Her deliberation however is very much framed within national, electoral politics within liberal states (Feldman and Gellert, 2006), a frame strongly contested in Fraser’s elaboration of the value of representation (Fraser, 2005). Like Sen, Fraser argues for the importance of deliberation: participatory parity is both processual (a process of deliberation from a position of equality) and an outcome (all are enabled to participate in society as peers). Thus deliberation is a procedural condition for fair access to all ‘substantive’ (economic, political, cultural, affective, environmental) goods. Fraser is more concerned with the troubles of consensus however: is agreement reached because of Habermas’ ‘unforced force of the better argument’ or because of relations of domination and subordination? As Fraser argues, there are many publics with

⁴ *Bodily health and integrity*: Being able to have good health, including reproductive health; being adequately nourished; being able to have adequate shelter. *Emotions*: being able to have attachments to things and persons outside ourselves; being able to love those who love and care for us; being able to grieve at their absence; in general, being able to love, to grieve, to experience longing, gratitude, and justified anger; not having one’s emotional developing blighted by fear or anxiety. *Affiliation*: (a) being able to live for and in relation to others, to recognize and show concern for other human beings, to engage in various forms of social interaction, being able to imagine the situation of another and to have compassion for that situation; having the capability for both justice and friendship [...] (b) having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. *Practical reason*: being able to form a conception of the good and to engage in critical reflection about the planning of one’s own life’. For a full list see Nussbaum (2003: 41-42).

multiple interests. She also qualifies ideas of what constitutes the public, both in terms of the public/private separation, and the separation between the state and civil society (Dean, 2009; Fraser, 1997).

In debates and differences between Sen, Nussbaum and Fraser therefore, questions of deliberation are central. A life to be valued can be discovered through reasoned arguments, but in the public sphere. There is a more expansive definition of the public sphere than is to be found in Rawls and Nussbaum with thinkers such as Benhabib, Habermas and Fraser emphasising the importance of civil society and the myriad forms of associational life that make up 'civil society' in contemporary democratic states: "It is through the interlocking net of these multiple forms of associations, networks and organisations that an anonymous 'public conversation' results" (Benhabib, 1996: 75). There is a special place made for the 'reasoned arguments of affected individuals', but from a position that begins with those affected persons, it is difficult to see how in a world of inequality, all people can have equal opportunities for deliberation (Erman, 2012). Indeed, in the specific case of disability, this is precisely one of the critiques coming from the ILM – that for too long those imagined as disabled have been excluded from deliberation about what constitutes a good life, whatever the form of that deliberation (judicial process, media, parliamentary debates etc).⁵ Domination, whether manifest in paternalism, institutionalization or medicalization has meant that people who are disabled have been excluded from decisions about their own lives, and their perspectives systematically excluded from practice, analysis and theory, at times with truly horrible consequences. Histories of institutionalization, sterilization and industrialized killing demonstrate how disabled people have been treated as less than human. Furthermore, some of these forms of oppression have been regarded as types of 'care', and from the 1990s there has been a significant critique of feminist care by disability scholars who have analysed care as entailing complex oppressions (Sivers 1997; Saxton et al. 2001; Priestley 1999; Morris 1991). These scholars have in part drawn on capability approaches, as well as feminist and anti-racist struggles to argue that it is socially constructed environments and environmental 'dis-enablings' that result in people with certain traits being 'disabled' and obstructing independent living (van den Brink et al., 2018: 12). Independent Living Movements (ILM) have also rejected notions of 'care' as applied to disabled people, promoting a contractualised model of 'personal assistance' (rather than 'care work' or 'carers') where people choose and train workers who provide services under contract. The Austrian policy described in the national study has been strongly influenced by the Independent Living Movement (ILM) which rejected the language of care as subordinating and demeaning, and prized self-determination and autonomy.⁶ Protesting at infantilisation and objectification and rejecting the paternalism of able-bodied professionals, the ILM demands a self-determined life for disabled people and tools to enable them to control their own lives and support systems⁷. Dependency is "created amongst disabled people, not because of the effects of the functional limitations on their capacities for self-care, but because their lives are shaped by a variety

⁵ The case of social media raises other issues, explored in ETHOS work package 4.4.

⁶ Policy explicitly states: 'Inclusion and maximum self-determination of the lives of persons with disabilities shall be achieved through the personal budget' (Meier, 2018: 3).

⁷ Consider for example the following exchange between Barbara, a nurse, and Adrienne, a disabled older person: 'Barbara argues that what you should do is change the temperature of the water from hot to cold... That would be good for the blood circulation. Adrienne says she agrees. Barbara reacts cheekily but with a smile: 'It doesn't matter whether you agree. I am saying that it is beneficial to your blood circulation' (Knijn and Hiah 2018: 31).

of economic, political, and social forces which produce this dependency” (Oliver 1989: 17). Thus dependency is stigmatized. While acknowledging the achievements of the disability movement in foregrounding independence, Kittay observes that achieving independent living is not possible for all disabled people, referring to her child who has both intellectual and physical disabilities (check): ‘No, I don’t take independent living as Sessa’s goal, as much as I admire it as an aim for so many other disabled individuals. Independent living is a subsidiary goal to living as full and rich a life as one’s capacities permit’ (Kittay 1999: 172).

There has been very little cross-fertilisation between the policy and conceptual work of disability studies on the one hand and long-term elder care on the other despite the fact that the boundary between ageing with disability and ageing into disability is very fuzzy experientially. In contrast to the disability literature, the literature on ageing has mainly drawn on the feminist ethics of care. There the focus is on the relationship between care worker and care user, attentiveness and personalization. Independence is also prized by this sector, but it is more associated with ‘ageing in place’ and delaying institutionalization which is generally considered more impersonal and restrictive than home based care (Knijn and Hiah 2018: 42). There have been efforts to bridge disability and feminist approaches (Shakespeare 2006; Williams 2009; Kelly 2014). Kittay for example (2011) has argued that all people move in and out of dependency, and that society must accommodate this fact, and in so doing turning dependency into a resource that connects, rather than an aberration. She argues that if autonomy is not taken as the norm for all human interaction then alternatives other than paternalism become open to us (‘co-operative, respectful, attentive relations’ Kittay 2011).

In ETHOS Deliverable 5.2 we suggest the development of a ‘mobile theory of justice’ that takes movement, past and present, as the norm rather than the exception (Anderson and Dupont, 2018). Mobility is a key challenge for many people who may find themselves disabled by poor access to public transport or non-adjusted housing, and indeed the examples in Sen’s foundational texts on Capability Approach are often related to movement. One of these is the resource of a bicycle which can be used as a means of transportation only if a person has certain characteristics (two legs, knowledge on how to ride a bicycle) and is socially allowed to ride the bicycle (in some societies it is not seen as acceptable for women and girls). Mobility also figures in Nussbaum’s list of capabilities under *Bodily integrity*: ‘Being able to move freely from place to place, being able to be secure against violent assault, including sexual assault, marital rape, and domestic violence’ (Nussbaum, 2003: 41). Mobility is a necessary element of capability sets that enable a person to perform certain actions: ‘Her home has been adjusted in order to be able to move around autonomously without a third person’s help’ (Knijn and Hiah, 2018: 32).

3) Methodology and national contexts

This Deliverable draws on mini-ethnographies and semi-structured interviews conducted with care users, care workers, disabled people and personal assistants and, in some cases, with their family members in Austria, Turkey, Portugal, Hungary and the Netherlands. These mini-ethnographies were written up as national reports that also outlined the national legal and policy framework in these states. We analysed the national reports for key common themes related to justice claims in the terms in which they were expressed by the ethnographic participants, that is their own sense of what is and is not just (or ‘fair’). There is a huge literature on care and justice, rooted in many

different paradigms and theories. However, our task was to specifically consider Capability Theories of justice, and we focussed on what gaps, tensions and possibilities the ethnographies indicated for these theories. In the context of the ETHOS project and its philosophical method which proceeds from the empirical to the theoretical, we take a 'bottom up' approach and foreground what can be learned by bringing the empirical findings, shaped by very different institutional and personal contexts, into conversation with each other and with capability theories.

Ethnography is a useful method through which 'to explore 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. It is therefore particularly useful in researching relationships and non-verbal communication. Ethnographies can last years and involve immersion into a world of practices that researchers must familiarise themselves with. However, mini-ethnographies are much shorter and can consist in focussed field visits rather than embedding. In a European context, embedding in a private household is likely to be regarded as intrusive and raises financial and resource issues. It is also likely to have a significant impact on the observed relationships. We opted for focussed field visits with some researchers accompanying care workers over the course of their working day across multiple sites, and others following care/personal assistant users for a period of time. In both cases researchers took part in activities with workers and care users as appropriate.

We conducted a training for field researchers as part of our ETHOS annual meeting, including on relevant ethical issues. Fieldwork could be demanding. Researchers were sometimes concerned about intrusion in the private space or found that there were emotional demands made of them: 'During all the observation all care users begged for attention, asking questions on why I was there and telling their life without me having to ask anything' (Brito, 2018: 51). The presence of fieldworkers was also appreciated by some service users: 'Anna remarked that she was happy she could do something for the CEU, that she could make a small contribution to normality, to a more peaceful world, to a world that was less rabid and mad' (Veres, 2018: 24). The case study protocol that was used to guide the national research is attached in Appendix A. A detailed description of methodology and sampling from all national teams is to be found in the D5.3 Methodology.

Access to conduct mini-ethnographies was challenging for all national teams, particularly in the time available. Given the very different cultural and institutional contexts we did not require studies to be directly comparable but rather were concerned to generate reports that would enable us to contribute to the theorising of justice by accessing felt experiences of injustice within the structural context that underpins them. Temporal constraints also meant we had to be flexible in our requirements. We did not insist on restricting the study to disabled people in youth and middle years but were open to the inclusion of people who had become disabled with age. Because of the potentially complex ethical issues involved we did not include people with cognitive impairments. We emphasised that we were interested in good relationships and that we were not trying to catch people out but to reflect the complexity of these relationships.

This has given us a wide range of service users and providers and types of relationships. Table 1 indicates the range of the national case studies.

Table 1: Ethnographic participants by country

Country	Service users	Service providers	Provision: private/ state
Austria	One blind single, one blind couple, one person with cerebral palsy	Students, household help, self-employed personal assistants	State
Hungary	An older woman recovering from an operation, one person with cerebral palsy	Two retirees, one professional physical therapist	Private
Netherlands	One disabled older woman, one married couple both with long-term care needs	One district nurse, one homecare nurse, one nursing auxiliary	State
Portugal	One housebound older man, one elderly woman, one elderly couple in an institution	Four professional care workers	State
Turkey	Two elderly couples, two older women, one older man all with long-term care needs	Live-in migrant care workers	Private

With the exception of Turkey, it is notable that all care workers/personal assistants were nationals, and, in only one case, Selma in the Netherlands, was the care worker a woman of colour. This is likely to be a consequence of methodology and challenges to access. As described in the individual country reports and methodological note accompanying the national reports, researchers often struggled with access given the intimate location (the private household) and the time constraints of the project.

The ethnographies were conducted in private households. In the Portuguese case this was supplemented by a study of an elder care institution. In the Netherlands and Portugal ethnographers started with the care workers, accompanying them as they moved between different homes, but these were still the private spaces of the care users. The nature of the latter's dependence on non-family members and of our method means that we were afforded greater insights into care users' personal lives than those of the care workers. Both the prism of care, which focusses on the vulnerable elderly in terms of their care needs, and the prism of 'independent living', which asserts the rights of the disabled person to control their service provision, prioritise the needs and rights of service users rather than workers. There are likely to have been many needs of the care workers and personal assistants that these mini-ethnographies did not have the opportunity to engage with. However, we did have the possibility of engaging with both parties, and in some cases also with family members, offering multiple views on intersecting relationships.

Each of these states has different ways of institutionalising and organising care and different care cultures.⁸ In brief, the Portuguese state requires households to take on considerable responsibility for care work. While the state has political responsibility for organising social protection and administering the welfare state, it often does so through the Private Institution for Social Security (IPSS), a non-profit institution ‘giving an organised expression to the moral duty of solidarity and justice between individuals’ (Brito, 2018: 9). Responsibility is thus divided in often quite complex ways between family, state, third sector and market. Support is available for ‘the satisfaction of basic need and/or activities of daily living’ (Brito, 2018: 13), though the objectives are ‘to contribute to the improvement of the quality of life of individuals and families’. In Hungary care for disabled people is heavily institutionalised but the constitution of 2011 enjoins families to care for the elderly, and the family is the main source of care for older people. The cost of eldercare, whether provided by nursing homes or home care, is high, and for most families it is not affordable on a long-term basis. A care allowance disbursed by local governments is available for family members who provide long-term care for a sick or disabled relative, but the care user must be severely disabled and meet three out of the following four criteria: unable to wash or dress without assistance; to use the toilet alone; to move around indoors without an aid; and to eat without assistance. Furthermore, the allowance is only one third of the minimum wage. Those who can afford it may pay themselves for informal care, which is about half the price of formal provision, and families employ both Hungarian and migrant care workers. Turkey too takes the provision of care by family members as the default option, with the Turkish state taking over when there is no legally responsible relative. Institutional care is growing but still relatively rare. Family members who provide 24-hour care for a person with severe disabilities can receive a cash payment if the household income is below 2/3 of the minimum wage and the person is assessed as having a disability of 50% or more. In Turkey many of those providing commodified care are international migrants, and there have been some attempts by the Turkish government to regulate their situation both in employment and immigration terms.

The Netherlands and Austria have more fully commodified systems. In the Netherlands Dutch citizens have a statutory right to give and receive care. Home care can be provided by home helps, care assistants or community nurses depending on the level of need (Knijn and Hiah, 2018: 14). Services may be delivered by an accredited service provider. Local authorities can also offer a personal budget (Persoonsgebonden Budget/PGB) for people to buy care services and equipment, including through financial agreements with family members. Support is available for housekeeping, shopping and other daily activities. ‘Cash for care systems [...] are available for all forms of care intended to promote a competitive market, to promote independent choice and self-responsibility of care recipients’ (Knijn and Hiah, 2018: 15). In Austria there is a distinction between care allowance and personal budget. Both are designed to enable people with support requirements to organise and pay for the care services they need. The care allowance can be used to pay for care in private settings, including by family members. The personal budget is for personal assistance in activities not included under the care allowance, such as accessing leisure services and with a view to promoting ‘the inclusion and maximal self-determination of the lives of persons with disabilities’ (Meier, 2018: 8). To make this easily accessible there is a service voucher system that insures assistants against accidents (though not against unemployment, sickness or pensions) (Meier, 2018: 12). Thus, in contrast to Hungary, Turkey and Portugal, in the Netherlands and Austria there are funds available that go beyond the basics. However, the amount available in both instances varies by region/municipality since sub-national authorities have

⁸ For a full policy background and comparison, see the national reports and ETHOS Deliverable 5.4.

responsibility for implementing national policy. This has significant consequences for service users as well as providers. While eligibility may be contested (Knijn and Hiah, 2018: 15-16), having a clean home and being able to participate in leisure activities are acknowledged as not being luxuries. In both countries the system positions citizens as able to participate and make choices regarding the kinds of care that they want.

Across Europe, the care/personal assistance labour force is disproportionately female, and in the case of eldercare, women are the majority of care recipients (Daly and Lewis 2019). Women are also more likely than men to be the informal care providers that do the unpaid work of ‘family care’ of children, elders and disabled people. As Brito (2018) points out, in Portugal, family care is largely women’s responsibilities and daughters/daughters-in-law play a crucial role in eldercare provision. Thus law and policy that emphasise family care for elders, such as that described by Veres (2018) have particular implications for women. In some, but not all of the countries participating, there are significant numbers of migrant women working in the eldercare sector, although not per se in home care (The Netherlands) and personal services (Austria). This is particularly the case in Turkey, which has become a magnet for labour migration in the region, with live-in domestic and care work being a key sector. Migrants, largely from Moldova, Romania, Ukraine, Georgia, Turkmenistan and Uzbekistan are usually employed to provide live in care, while Turkish women are more likely to perform housework. There have been attempts to regularize and integrate migrant care workers and to formalise employment relations, with mixed success (Akkan and Serim 2018). In Hungary too migration is an important source of eldercare provision. This has been somewhat invisibilised, because the migration has tended to be of ethnic Hungarians whose mother tongue is Hungarian, coming from neighbouring Romania and Ukraine, working informally in relatively well-off households. However, there has been a shift more recently as Transylvanian Hungarians (citizens of Romania) declining and more internal migrants from within Hungary moving to more prosperous areas of the country to do this work (Veres 2018).

Finally, we should note that this is not a comparative report. The institutional contexts, participants, histories, and cultures of care in five different countries mean comparison would demand far more resources and time than were available. Researchers responded very differently to the challenge, and research participants were also varied: some people were disabled and others frail elderly, some living alone, and others with relatives on hand. Rather than produce a comparative report we read and coded national studies, contextualising and comparing themes that emerged through bringing them into conversation with the theoretical literature.

4) A tale of two service users

The focus on commodified care in private households requires us to consider how to accommodate particularity. We have therefore chosen to start the discussion of everyday claims for justice in these relations by examining two very different examples taken from the Portuguese and Austrian case studies. These examples seem to call for different conceptual framings in order to analyse how claims for justice are negotiated and reflect on the usefulness or shortcomings of Capability Theory. We will first outline participants’ situations and relationships before discussing the insights that Capability Theory offers in those instances and conversely, what these cases tell us about Capability Theory.

Antonio

Antonio is 71 years old and suffers from severe rheumatism. He has significant mobility problems, needing help to leave his bed, move around his home and do the basic activities that are necessary for survival. He lives in the Portuguese village he was born in – though he left for work when he was 18 – and in his parents' old house. It is damp, cold and dark, and smells unpleasant. He lives alone and sees no one apart from his sister on very occasional visits. He is very lonely, often bored, and feels trapped inside: 'I wish I could go outside more often [...] I guess it's the more unfair thing, not having someone to go out with me, the girls can't, they don't let them' (Brito, 2018: 32). The 'girls' are Maria and Ana, care workers from the Home Support Service, which provides a state funded mobile unit that visits him twice a day. In the morning they help him get out of bed, wash and dress him, prepare his breakfast and install him in front of the television. In the middle of the day they bring him his lunch. They do their best in the short time they have available to care for him, including by breaking institutional rules and bringing back his laundry more often than they should, as a response to the smell in the house. He appreciates their care, distinguishing them from some other workers who treat him 'like a bag of potatoes'. They are concerned about his life and feel he is in a miserable situation: 'Antonio doesn't receive any visitors, neighbours give him little or no attention: "He looks like an abandoned dog", Maria tells me with a certain pain in her eyes' (Brito, 2018: 23).

He is not content with his life, and one day his desperation to go out of the house is such that he damages the door that has been locked precisely to stop him from leaving the house on his own. He is reprimanded and reminded that concerns for his safety means he cannot go out alone. The care workers are resources that are being put into enabling Antonio to endure but he is not achieving 'beings and doings' that he values. While the resource of a beautiful park might be available for Antonio, as it is for other residents, he does not have the means to convert this resource (the beautiful park) into an outcome that is valuable for him (the 'doing' of being seated on a bench on a sunny day). Antonio is not in a position to enjoy several of Nussbaum's central human functional capabilities. He is not able to 'move freely from place to place', he longs for attachment to persons outside himself, but the opportunities are largely limited to the care workers, and his opportunities to 'live for and in relation to others' are stunted. His situation signifies a profound challenge to public policy in meeting human needs. Arguably Antonio is largely being 'required to rest content with mere bare humanness' rather than enjoying a 'basic human flourishing' (Nussbaum, 2010: 310).

Antonio appreciates caregivers' work, and there are no overt conflicts of interest between them. Indeed, they share a common interest in suffering from the lack of investment in this service. He feels they are underpaid and undervalued. This is also reflected in his appreciation of Maria and Ana, an appreciation that is intrinsically gendered: 'It takes a very big heart to do this work and they work hard. But some people don't value their work, they must think it's nothing special, but it is, they are taking care of people. It is almost as they are a mother, and being a mother is beautiful' (Brito, 2018: 33). Potential points of conflict are avoided by evasion and by what could be described as a kindly deceit (cf Brito, 2018: 59 - Table 5). Care workers have hidden kitchen knives because they are concerned that he will accidentally harm himself and he is convinced that there are thieves who have come in and stolen things. The flipside to Antonio's explicit characterization of Maria and Ana as maternal type figures is his infantilization: if they are the mothers, he is in the position of the child. They are the situation together, as women and children. The alternative to this infantilisation is deliberately turning a blind eye. Brito describes the response to his attempts to break out of the house thus:

They explain to him: “You know that you cannot leave the house alone [...]” Antonio answers: “Not alone, nor accompanied, I don’t leave the house!”. Silence. Caregivers don’t insist on the subject and they dress him and take him to the kitchen to have breakfast.

(Brito 2018: 27)

Both parties are at an impasse. The care workers are not able to respond to Antonio’s clear statement of his wishes, through no fault of their own. They do not have the resources to respond to his assertion of decision and choice which is to treat him as an adult, and faced with an insurmountable problem there is, in this situation of intimacy and dependence, silence rather than conflict.

There are multiple factors that limit Antonio’s capability sets. Most obviously, his arthritis impedes his mobility, but there is also his lack of financial resources and family networks. These limitations are shaped by the political, economic and social context, including gender and gendered familial relations. The fact that he is a single man means that he must rely on his sister, and he wishes that she lived with him, but his sister lives with her husband in a different village, and she visits only occasionally. He is provided support at home to avoid institutionalisation, but Ana and Maria believe that living in an institution might make him happier even if it will make him more ‘dependent’. They feel that he badly needs to spend time with other people and should at least be able to access day care. This is not in their purview however as it needs to be arranged by social assistance: ‘I don’t understand why they don’t make the effort for Antonio [...] Poor soul [...]’ (Brito, 2018: 24). These measures will cost money, and the care workers intimate that prevention of institutionalisation might in part be a cost saving measure. Yet this is not only about financial resources but also social environment. Antonio’s loneliness affects his ‘conversion factors’, and this isolation may partly be related to his life history, but also to social norms about gender, the elderly and elder care. Trapped in his house, Antonio is literally not ‘seen’, and his claims (to leave the house) are heard only by his care workers who do not have the power to respond to them.

The consequences of knowing the needs of the elderly people they care for reach into care workers’ personal lives, with stress, burn-out, depression and an inability to relax when they are not working. Maria and Ana have both worked for HSS for 15 years. The vast majority of the staff in the Home Support Service are female. They are professional care workers and do not simply perform tasks but engage with Antonio, take an interest in his life and his emotions. Maria and Ana know that what they do is not sufficient to afford Antonio a decent quality of life: ‘Antonio [...] that isn’t life. There he was, left alone. It’s terrible, it breaks my heart’ (Brito, 2018: 25). Through small acts of kindness they actively sought to make his life, and the lives of others they cared for, ones that service users had ‘good reason to value’.

Maria and Ana have both worked in the sector for over a decade, and a life that has value for them includes not just performing work tasks but providing *good care*. ‘A good caregiver cannot go to work by force. You have to like what you are doing. If not, it’s better to go and find another job’ (Brito, 2018: 30). This is not only for Antonio’s sake, but also for their own life satisfaction. Following Nussbaum’s account of human capabilities, their work was orientated toward the capabilities of emotion, practical reason, affiliation and control over the environment, but the conditions within which they worked meant that these were difficult to realise. Thus, like many of the very dedicated care workers we are introduced to in the national case studies, Maria and Ana felt that despite all their efforts they were not able to give the level of care that they would have liked.

Case study 2 ('CS')

'Case Study 2' in Austria (pseudonyms were not supplied) comprised a mini-ethnography with a partially sighted and disabled father (for the purpose of this report referred to as CS), a blind mother, and their three children aged 6 months to seven years. Both work outside the home. They need assistants for mobility, household tasks and childcare and have seven personal assistants whom they pay to be on standby for one day a week. The personal assistants are employed under the service voucher arrangement. The relationship is formal with the service user directing the personal assistant in the performance of tasks ('the father instructs the assistant to empty the washing machine and to hang up clothes while he changes the baby's diapers'), but with polite conversation ('the assistant and the father talk in a friendly way about several issues. It appears that they have known each other for a while. They talk about good and bad neighborhoods. The father is quite self-determined, the assistant is quite passive' (Meier, 2018: 24). The relationship is very much informed by its emphasis on the competence of the service user and personal assistants are expected not to participate in decisions or social interactions and not to share opinions. CS regards the personal assistant as an extension of his physical body and indeed says he would prefer to have a machine rather than a person performing this function if it were possible. While polite to personal assistants one-to-one he considers that they should be as invisible as possible to others:

If I am in some meeting, I always do it the same way when I introduce myself: 'And to my left Miss X is sitting. You don't need to pay attention to her much. She only needs some air to breathe.

(Meier, 2018: 29)

Do you [...] thank your eyes for their existence every day? No. But that doesn't mean I need to treat them like dirt.

(Meier, 2018: 29)

The idea that the personal assistant is a replacement for body parts that are not working is a manifestation of how personal assistance is regarded more generally in Austria and is not particular to CS (Meier, 2018: 6), though CS is the most 'extreme' illustration of this model among the three ethnographic studies conducted in Austria. The relation is highly contractualised as between an employer/team leader and a worker contracted under a service voucher arrangement, and assistants are actively discouraged from becoming implicated in the family relationships:

Duties encompass assisting the service users in childcare, but not [...] providing childcare services. The service users put a lot of emphasis on differentiating between this. It is important for them that they themselves care for their children and not the assistants [...] They draw a lot of attention to not mix up private life, friendship and personal assistance.

(Meier, 2018: 22)

Conflicts are managed formally. To minimise conflict and establish the framework of service provision, service providers are given a set of some 50 rules, constantly updated and issued at the beginning of each month. For example:

In case the requested good is not available in the suggested shop, do NOT go unauthorised to another shop [...]

Please only wash the dishes upon request by us [...]

Please only describe what you see (e.g. son eats sand) and do not comment on what we should do with this information.

(Meier, 2018: 22-23)

The rules were developed according to CS in order to facilitate clarity, transparency and equal treatment between the personal assistants and ensure a clear boundary between work and friendship. When assistants made a mistake they were sent a written reminder of the rules. Previous work on relationships between domestic workers and their employers, in heterosexual couples has found that while the woman typically manages the domestic worker, the contract is usually signed by the man. The husband deals with contractual elements, and the wife with emotional ones. This suggests that while this arrangement, ostensibly divested of emotional contact, is treated as purely contractual, it is nevertheless highly gendered, and gendered as male. Personal assistants are actively discouraged from contacting each other as the service users considered this would jeopardise their control over timetabling and other aspects of the relationship. The exchange with the ethnographer was also monitored:

The interview with the assistant takes place and the father asks if he is allowed to be present. The interviewer refuses the presence and the father leaves the room. However, during the interview, the father repeatedly enters the room or stays in front of the door where he is able to hear everything.

(Meier, 2018: 24)

In contrast to Maria and Ana, who found managing the institutional limitations of their role difficult, the personal assistants express little urge to be 'more than that'. They are clear about the priority of not interfering with the autonomy of the service user in keeping with the approach of the arrangement under which personal assistants are contracted. The transactional nature of the relationship and their heavily instrumentalised positionality are not objected to although this is not always straightforward to manage:

You basically hold yourself back and are really only the substitute, like it's here, the substitute for the eyes and maybe the hand, but not more, and it's also that one is aware of that, that you are not more than that.

(Meier, 2018: 31)

Service voucher work is based on precarious, short-term (maximum one month) contracts that can be renewed repeatedly. Workers have no sickness, pension or unemployment protection, and no holiday pay. Yet it seems this is tolerated by assistants, who are more concerned with the demarcation of tasks and responsibilities. They do not have to perform intimate body work and find their conditions 'flexible' rather than exploitative. Notably the majority of personal assistants in the three Austrian case studies are students, not people for whom their role is a vocation or a long-term prospect ('During my studies, fine, but not after that. It does really impede liberty a lot.' [Meier, 2018: 60]). They are at a life stage when they do not themselves have personal caring responsibilities, in contrast to Ana and Maria who were having to manage their own households as well as their working relationships. The workers related to in the course of the research were female and the majority of the group of seven were female, but two or three of them were male. However, the contractualised nature of their work, the lack of intimate personal care, and their life stage contribute to explicitly gendered experiences of personal assistance taking a back

seat. While for older workers insecurity might be undesirable, in the case of students the temporariness of the work seems to be part of what makes it attractive. Several feel that the opportunity to work as a personal assistant contributes to their wellbeing and personal development: 'I find it very exciting and because of course somebody else is helped by that, then it's somehow this win-win situation, and that's why I found it so exciting and I really like it' (Personal Assistant Care User 1, Meier, 2018: 43). Their recognition of the nature of personal assistance also helps them accept the instrumentalism of the relationship. This is effectively what they signed up for and, in this particular case, the heavily contractualised, managed and boundaried nature of the relationship means that conflicts can be resolved with reference to the rules and contracts.

The ethnographer finds that 'the service users are living the life they want' (Meier, 2018: 27), placing a high value on self-determination and considering that they have achieved this. In the language of capabilities, CS has a life he has 'good reason to value'. His individual characteristics, social resources, and access to personal assistance all facilitate this. The personal assistants are resources that contribute to a capability set and enable a desirable functioning. The service is a response to the demand for justice in terms of self-determination that is both recognitive (recognising autonomy) and redistributive (providing the means to enable those who have been socially dis-abled). In Capability terms, public policy provides a resource that improves individual conversion factors in the face of social norms and environmental infrastructure. The transactional nature of the relationship is facilitated by the social position of the personal assistant.

Antonio's need for physical support is very different from that of CS. He needs assistance with intimate hygiene and moving around the house. He also has little contact with people apart from the care workers, while CS works and has a young family and partner and can draw emotion and affiliation from other resources. These are matters that are personal, but also of course have social components. One problem for Antonio and the care workers is that he has no network of kinship and neighbourhood ties. He is solely reliant on the input of the care workers, making that relationship both highly dependent and demanding.

For both Antonio and CS there is a clear policy or political value to taking as a starting point a 'life one has good reason to value' in one's analysis of their situation. But how is this related to justice? It is too easy to dismiss Antonio's situation and to see an old man fumbling with the door locks. Yes, it is sad that he cannot go outside the house, but can it really be said to be *unjust*? If CS is unable to go outside because of his blindness the relation between this and structural injustice is relatively clear. While he personally might not have been politically active, he is a member of a collectivity that struggled against subordination and exclusion to achieve access to the resource of personal assistance in order to be able to socially participate. Antonio cannot leave the house in part because of his rheumatism and isolation, but perhaps it is the fact that he is an older person that obfuscates the issues of justice. This is precisely where Nussbaum's central human functional capabilities is helpful: it allows us to start from Antonio's situation and his inability to for example 'engage in various forms of social interaction'. His aspiration to leave the house is not a justice claim per se, but his inability to participate as an equal in achieving, or even to claim 'beings and doings' that he values is a symptom of institutionalised injustice and helps us understand the kinds of elements that make his situation so unsatisfactory. He seeks connection – whether it is to visit the city, to have more time with the care workers, to no longer live alone.

Central capabilities offer a means both to trace how this can relate to a more generalised claim and to be more confident in asserting it as such. It is in this scalar transition, from the particular and the (apparently) minor to a claim for justice that capability theories might indeed be helpful. In contrast to Antonio's case, CS focusses on

recipients of the personal budget which is a response to the specific justice claim by disabled people for self-determination. Thus it is easier to appreciate the context of the relationship between CS and the personal assistant as coming out of a claim for justice that is being made for and by a group of political actors, a claim for recognition of autonomy. The logic of that claim is followed through in the highly contractualised nature of CS's relations with the personal assistants and the ways in which potential conflict is averted (through clarity about the rules governing assistants' responses and behaviour).

Antonio wants to be listened to, and that first step in the deliberative process is not being permitted. How can people who face multiple political and social exclusions participate in deliberative processes? Deliberating suggests at least formal equality, but concretely, how can Antonio deliberate when he has a painful condition, is confined to his house and when his sense of self-worth has been eroded by loneliness? Maria and Ana would like to speak for Antonio and make claims on his behalf, but they have neither the authority to do so nor a place to go with their claims. The HSS sets the rules but they have very little interaction with the institution and no negotiating power. This means that to manage the situation they are required to infantilise him, locking him in and hiding things when they would prefer to advocate for him but have very few tools to do so.

This is very different from the situation of CS who one suspects would be understandably insulted if offered an advocate, and who actively participates in deliberation about his and his family's lives. Indeed, the justice claims that one can imagine arising in this situation are more from the situation of the personal assistants. All parties expressed satisfaction with the contractualised framing of the relationship, despite the fact that workers are low waged and kept on permanently temporary contracts that deny them many worker rights. However, there were no attempts to make such claims, indicating that differences in workers' characteristics and roles is also highly relevant for bottom up senses of injustice. Personal assistants are not professionalised but are laypeople who are there to perform the instructions of their employer. In fact, CS is quite an 'extreme' example, and the other budget recipients' negotiation of the relationship with their personal assistants was more ambivalent. They are not invested in the status of their work, nor are they wholly economically dependent on it, but above all it was a temporary role.

As noted above, CS and Antonio represent two very different ways of imagining the relationships between the users and providers of commodified support services. These differences are partly structured by policies, by personalities, by gender and by disability type, among other factors. Characteristics, employment relations and roles are inter-related: students in transactional precarious work as personal assistants are task oriented; professional and full-time workers, like the care workers in Netherlands and Portugal, are emotionally invested in the longer-term lives of their clients. However even people who work alongside each other can have very different attitudes to and interpretations of the relations under which they work. For example, Brito describes two care workers who are on the same shift in the same care institution, Raquel and Helena. Raquel is younger and came to the work because she was unemployed after leaving education, while Helena has been working for much longer in the sector. Raquel tries not to get too emotionally attached ('I know that someday they will die, and I don't want to suffer too much with that'), while for Helena 'even if the work is hard, the emotional side makes it worthwhile' (Brito, 2018: 47). It is striking how their likes and dislikes parallel each other. For Raquel the best part of her day is lunchtime when she helps people to eat; for Helena it is the worst time of day because there are too many people all together. For Raquel the worst time of the day is after lunch when the older people need to be taken upstairs for their nap, when she herself is also tired. For Helena in contrast this is the best time of the day: 'It's very sweet,

some of them have their own routine and always ask for hugs'. Helena feels that care workers can be like part of the family, whereas Raquel does not (Brito, 2018: 47).

In sum, the guiding principle for justice of a life one has good reason to value can be helpful in the case of frail elderly and disabled people, but the question remains of how and who decides one has such a life if it is not the person living it. Listening to the voices of the people concerned is clearly critical but feeling one is *being heard* is not the same as *deliberation*. This suggests that appreciating the relation between participation, representation and deliberation, even if it is not addressed in these terms, matters to people's understandings of how they are situated in particular contexts of social and political marginalisation. In addition, even in these very different situations and relationships we can see that some capabilities are created by connection with others, commodified or otherwise. There are very different models through which users and providers of support services understand these connections and the relations engendered by commodified care practices. We now go on to consider what this means for Capability Approaches/Theory.

5) Capability: Independence, Connection and Gender

While we have described the difference between the language of the ILM and care, both place considerable emphasis on the autonomy/independence of the older person or the care user. 'Independent living' for older people is often associated with living in one's own home or with a family member as opposed to an institution (Knijn and Hiah, 2018: 57; Brito, 2018: 12), though it should be noted that this idea is not shared across national contexts. In Turkey for example it is necessary to demonstrate that one is sufficiently independent to carry out daily activities in order to be eligible for elderly institutional care; in the Portuguese study, Susana and Paulo did not feel safe living just the two of them when their caregiver emigrated. They thus opted to move into a nursing home precisely because they felt it would preserve their independence. However, they were disappointed with the limitations they experienced in practice: 'We came here by our own will. But I guess that it could be better, we could have more attention, more liberty' (Brito, 2018: 44). What was common across all the studies was that, from the point of view of the care worker, the service user's home was their space. Not only was it more familiar but it was also a space where the care user had more agency and authority and was therefore able to follow their own ways of doing things.⁹ The ethnographies reveal that the home was a space that live-out workers negotiated with care.

Selma never enters the bedroom, nor the kitchen or the seating area in the living room. Selma only treads where the care activities take place, which is in the dining area, the living room and the bathroom. Selma only heads over to the seating room area when she is helping Mr Jansen with the compression socks. In other words, Selma only enters areas of the apartment when there is a certain functionality to it.

⁹ This was expressed explicitly in the rules for the Portuguese home carers which stated: 'The user's domicile is inviolable and as such should be considered, not being allowed to make changes or remove goods and objects without prior authorisation' (Brito, 2018: 13).

(Knijn and Hiah, 2018: 46)

The live-in workers clearly had a different relationship to the home spaces, but the ethnographies suggest that the fact that this is the care user's home gives the care user a certain kind of authority over the use of space.

The physical space seems to be used equally both by care workers and care users. However, the space belongs to the care user, and how it is used by the care provider depends on the needs of the care user.

(Akkan and Serim, 2018: 16)

For care users, staying at home is not simply a measure of the independence one 'has'. It is about the authority one can claim. In the Hungarian study Anna finds that having books and notebooks accessible to her is an important element of her life. This makes little sense for the care workers, who regard these objects as out of place. They must also be dusted and require them to do 'often repetitive activities which at times look strange or pointless' (Veres, 2018: 26). The books make work for the care workers but are valued by Anna, who does not have to do the physical labour of dusting them. What matters is that in her house, the books must be looked after and kept in place.

In the case of the Austrian recipients of personal assistance, self-determination is the explicit aim, and the unspoken negotiation described in the other ethnographies is not at issue. Indeed, ensuring that service users have a sense of self-determination is an important part of the personal assistant's job ('to give the service user the feeling of autonomy, control and self-determination'). Previous research has found that 97% of service users consider they live a self-determined life, but only 60% of personal assistants agree (Esterer, 2012, cited in Meier, 2018: 14). This suggests that the scheme and the personal assistants are indeed succeeding in establishing a sense of self-determination on the part of the service user but also points to ways in which invisibilising inputs is an important element in maintaining a sense of autonomy, particularly when it is highly prized. This important and sensitive boundary work is performed by care workers as well as personal assistants:

Self-reliance must always be encouraged [...] It would be much faster for Adrienne if I would wash and dry her. But I do not [...] I would probably finish half an hour earlier if I took everything off her hands. But the result would be that in six months she can't do anything by herself anymore. She will have become completely passive, sitting in her chair and that is something that you have to prevent at all times.

(Knijn and Hiah, 2018: 52)

The justice claims of care workers are in part bound up with the justice claims of care users. They have a desire to give good care, and this is an important element in a life that for them has value. In this way the desired functionings of care workers and care users overlap. Each person has a unique set of conversion factors, but resources, conversion factors and capability sets of different persons are not discrete; they interact with each other. Hence, capabilities may also be conferred by connection with other people.

We all need others in order to be 'independent', and in general the more invisibilised the support the more assured the sense of self-determination. This is not only the case for the support given by personal assistants and care workers but also for support in formal employment situations – the work of administrators for example. For certain jobs, invisibilising support is in fact a key part of the role, and the work of someone who facilitates smooth

operations is not noticed unless they make a mistake. This invisibilisation is very important for the users of personal assistants. While CS takes this the furthest, it was also required by other employers:

That's very important to me that the work assistants are people who [...] if they are in the background [...] and I don't acknowledge them at all, and they still look after me in the background and maybe give me something to drink but are able to hold themselves back.

(Meier, 2018: 31)

While this is highly prized, in the case of care work (as compared to personal assistance) this invisibilisation can cause considerable stress, as described by Brito: 'The psychological pressure upon these workers is high, to the point that it is almost as if there was a disembodiment, as if they are not there' (Brito, 2018: 27). Eva Kittay has written about the 'transparent self' of the dependency worker: 'a self that defers or brackets its own needs in order to provide for another's... a self through whom the needs of another are discerned, a self that, when it looks to gauge its own needs, sees first the needs of another' (Kittay 1991: 51). Unlike the transparent self, invisibility is not tolerated on the grounds of having interests vested in the wellbeing of another, but rather because the worker has entered a contract. It can sometimes be experienced negatively by the service provider: 'What's not so good is you need to be able to hold back, to hold yourself back very well, and in many issues that's... difficult sometimes' (Meier, 2018: 25). Rather than 'transparency' this is more akin to the invisibility of the highly efficient university administrator whose efforts often largely get noticed when there is a problem. Many service workers who do not do 'body work' or intimate relational work must also make their efforts effortless. The distinction between the autonomous self with their individual characteristics and the social and environmental 'conversion factors' within which the autonomous self manages others is itself work.

Independence, connection, transparency and invisibilisation are inescapably gendered. The social reproductive labour necessary to maintain the idealised 'independent citizen' is invisibilised, and is largely undertaken by women (Anderson 2000). Our interdependence has long been emphasised by feminists, both practitioners and scholars, particularly with reference to unpaid (female) reproductive labour, patriarchy and its relation to capitalism.

Family/community care is also known to be highly gendered, and largely (though not exclusively) performed by women and unpaid. In all the country studies most of the unpaid care that was provided by female relatives (including daughters-in-law) except in cases when husbands were caring for wives. A gendered lens that acknowledges the feminised and unpaid nature of family care exposes a somewhat contradictory relation between family and (in)dependence national policies. As discussed above, non-institutionalisation is associated with 'independence' but the apparent self-reliance of the home is in fact 'built on the support of the family' (Veres, 2018: 32) – as the case of Antonio, who has no supporting relatives, reveals. In Turkey state provided institutional care is only available for those who are *kimsesiz*, or without a family carer. The Portuguese state is explicit about the division of its responsibilities between the family, the third sector and the market (Brito, 2018: 9), but the family (and its absence) proved critical in all the national case studies. Family engagement is explicitly but negatively recognised in policies which only provide support in daily activities to those who do not have available family members. For example, Adrienne in the Netherlands is only now 'living in a clean house', as she puts it, because she was not eligible to receive assistance with housekeeping while her son was living with her. The fact that her son was not prepared to do work associated with running a household was not admissible. While the policy seems to promote gender equality in its expectation that household residents will contribute to homecare irrespective of

their gender, its effect is to not recognise that this is not the case in practice, thereby reducing Adrienne's quality of life in the name of equality.

In all the country studies with the exception of Portugal, in certain defined situations family members who are providing care are eligible for a state allowance, and the majority of providers are female. In Austria for example two thirds of the recipients of family care allowance are female (Meier, 2018: 7). In Hungary, where a family member living with and caring for a severely disabled person is eligible for state provision amounting to one third of the minimum wage. The vast majority of the 53,000 people who receive this allowance are women in their 40s and 50s caring for their seriously disabled children. If the carer themselves falls ill for more than 45 days they lose their health insurance (Veres, 2018: 15). The 'family' rubric risks hiding the fact that it is women who are the chief care providers, and women who often withdraw themselves from the formal labour market in order to provide family care.

Even setting aside direct payment for care provision, family participation can be critical in determining quality of life, and this too is highly gendered. Family members contribute to what has been described as "'patchwork care' (Balbo, 1987) referring to the ways women stitch together different arrangements' (Knijn and Hiah, 2018: 21). The Hungarian study for example found eight different care strategies adopted by families to manage responsibilities for elderly members in Hungary, ranging from employing undocumented care workers to removing themselves from the labour market (Veres, 2018: 12). This patchwork can be exceedingly threadbare, as we saw with Antonio, but there were multiple examples in all the national studies of it being extremely well woven. The Portuguese study for example contrasts Antonio's situation with that of Ines, visited by the same care workers. Her house is bright and clean, notably thanks to feminised work (of her daughter-in-law rather than her son):

:

It is the daughter-in-law of the care user, walking behind her, who receives us. The elder [...] says: 'Today it's bath day!' and everybody laughs [...] They talk about preparations for the family wedding [...] They do not take it (the washing) to the institutional laundry, rather it will be the daughter-in-law who will take care of it. They take Ines into the kitchen and sit her down. The daughter-in-law arrives and says she'll make her a cup of tea. The caregivers say goodbye and return to the van.

(Brito, 2018: 24)

The patchwork appears particularly well woven from the viewpoint of care provision when the care worker lives in, and the Turkish ethnographies describe family members and workers co-operating in shopping and other routine work. In some cases, families provide support to care workers when they are in need, in the case of bereavement for example.

Paid workers can be interestingly ambivalent about their relation to family care even as they are often seen as a substitute for family care. They can be critical of families who do not provide the care themselves, thinking of care workers as second best to 'proper' family care, making up for things that family ought do: "If I see that it is really urgent, I accept, but when I know that they have children and grandchildren who can do it for them, I say no" (Brito, 2018: 26). However, from the perspective of the care user, paid workers may actually be preferable to family provision and many care users specifically sought to avoid being *dependent on family members*. In Hungary, Anna, an older woman recovering from an operation, preferred to pay care workers to temporarily live in rather than be

a 'burden' on her two children, both of whom lived very close by. Aron too was attempting to gain more autonomy for both himself and his mother – wanting her to build a life of her own that was not solely built around him (Veres, 2018: 31). This was the case across very different national contexts, including in Turkey where family care is promoted by state and culture: 'It is a good thing you are not dependent on other people in the family. Maybe my care provider is a good person and that is why I feel that way' (Akkan and Serim, 2018: 24).

Who or what one is dependent on matters. Unpaid assistance from family and friends can be experienced as dependence, but contractualised and commodified assistance experienced as assistance to be independent. It suggests that the term independence as used in these policies and policy debates signifies not only that one is self-governed, but that one is able to (is given the authority to) govern others. Often on the grounds that they have not been able to 'choose' their relationship. In contrast to family dependence, commodified support given by people who have entered into contract of their own 'free will' was considered assistance to be independent. Indeed the complexity around the relation between independence and family relations is what makes the gap that contributes to Antonio's loneliness and isolation. Independence in Portugal is strongly associated with non-institutionalisation and autonomy. Health ageing means 'the possibility of the person remaining autonomous and able to take care of him/herself in his/her natural environment' (ISS, 2014: 3). But the family is assumed to have a significant role in care provision – what has been described as a weak welfare state in a strong welfare society (Boaventura de Sousa Santos cited in Brito 2014: 9).

Antonio, in contrast to CS chaffs at the limitations of the contractual model – his comparison of care workers to mothers is noteworthy. As an alternative to the contractual 'story' of equal relations freely entered into he adapts the familial story of care. This is a model that has been challenged, not only by the Independent Living Movement but also by domestic workers and trades unions - the more like a family member, the less like a worker, and justice claims for wages, reasonable working hours and conditions are claims of workers not mothers. On the other hand, the more like a worker the more alienated and instrumentalized the labour, and as many of the care workers in the national case studies aver, it is the relationality of care that gives them pleasure in their work and makes them feel their contribution is recognized.

The relations between formal and informal care, and the management of these relations is also highly gendered. The weaving of this patchwork is directed by women. For example, the arrangements for the Jensen couple, described above, the (female) care workers are very conscious of the work that Jannie, the wife, puts in to looking after her husband. Mrs Jansen manages her husband's medical appointments and medicines, his diabetic diet, and the housekeeping: 'the care workers also interpret their task as to lighten the workload for Mrs Jansen as she tends to take all responsibility for the care of herself, her husband and their home' (Knijn and Hiah 2018).

How the care/service user experiences the relationship with the family member/care worker/personal assistant affects how they feel about their support. Several participants were sensitive to the fact that family members have not been able to 'choose' their relationship and are acting because they have to, in some cases they are legally required to be the primary source of support, but there are also social pressures at work. In contrast, care workers and personal assistants have entered into contract of their own 'free will'. Being supported by family and friends can mean the care user having to take the requirements of these agents on board too. One personal assistant contrasted her response to her disabled brother with her response to her disabled employer: 'When my brother comes and says he needs something, that I should go and get it for him, I will say: Yes, I will finish that first, and then I will come [... But] in her case I know I am there for that, and I am also paid for being here, so I also can't take

forever to do it' (Meier, 2018: 35). Thus, commodification shifts the locus of control over the relationship to the support service user.

While paid assistance and workers may be preferable to care from family members, the idea of family can be drawn on to manage relations in the home by both service providers and service users. Sometimes feeling that one is a 'distant cousin' or equivalent can help overcome embarrassment when care workers enter someone's private space for the first time, especially if they are performing intimate body work. As one care worker puts it: 'We kind of need to forget that we are "invading" their private space' (Brito, 2018: 28). In the Turkish study workers were often addressed in familial and affectionate terms as 'my dear' and 'my daughter'. This was reciprocated in some instances by calling the elderly person 'mother'. These familial terms can also be used to convey the worker's authority: 'Remziye (*care worker*) is my mother-in-law, she intervenes in everything.'

Despite the very different contexts, cultures and personalities described in the national case studies, what seems to be common is the concern to manage connection, and this is the case for paid care workers, personal assistants, family members and service users. It is most obvious for care workers and family members. Like the management of their own invisibility, care workers often have to manage the relationship with service users, striking a careful balance between care and professionalism. Moniek exemplifies considerable skill in managing professional boundaries deliberately and carefully. She has a 'thick' relationship with Adrienne. She brings her left-over spaghetti from her home, performs small acts of care such as feeding Adrienne's kitten, and keeps in touch with Adrienne's daughter about her well-being. Nevertheless, she feels the relationship is within professional boundaries, and indeed the ethnographer notes that Moniek is more reserved in her conversations about her personal life than is Barbara, the other main carer. Moniek says it is precisely because the boundaries are clear that she chooses and has this capacity to manoeuvre.

I can tell that I went to the beach yesterday. I can also tell that I went with my children. I can also tell them I have four children. But that's where it stops.

(Knijn and Hiah, 2018: 37)

While actions such as bringing in food or contacting Adrienne's daughter suggest that she is not operating according to strict boundaries, she is also notably more reserved than other care workers when it comes to discussing her personal life. She is helped in this professionalism by being part of a team, as also are the care workers described in the Portuguese ethnography.

It was not only the care workers who sought to manage their connection, but also the care users. They often seek a closer emotional relationship, especially if they do not have family:

There was also the case of a care user in a wheelchair who, every time someone passed by her, would reach out her hand to give a handshake. At the end she would pull the other person so she could receive a hug. The care workers explained that she does that to everyone, even people she doesn't know, and this can be seen as an example of the emotional demands of institutionalised people [...].

(Brito, 2018: 51)

Such actions on the part of the care users is typically characterised as dependency and demands. For this reason, professionalised care services can be arranged precisely to limit the opportunities for personal relationships to

develop (Knijn and Hiah, 2008: 47). However, these kinds of behaviours could also be seen as demonstrating that service users have something to give. They need to be recognised as people who can give and demonstrate care as much as receive it, as illustrated by Antonio's description of how he worries if the care workers are late because he thinks they may have had an accident. This is a call for recognition that is in some cases mitigated by the concern not to be too 'demanding', and most service users wanted to demonstrate that they care for the care worker - that they are not just seeing them as machines.

Ayca is also compassionate towards Linda, observing 'You have fed me, but you have not eaten your meal. Is there any food left for you?

(Akkan and Serim, 2018: 17)

Susana goes to the caregiver to have some conversation, to ask them if they need something – although due to her physical condition it's unlikely she could help the caregiver to perform any task.

(Brito, 2018: 43)

(Anna) was doing her best to make the caregivers' stay as acceptable as possible as she was aware of how difficult it must be for the caregivers 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 consequential and not act on a whim.

(Veres, 2018: 26)

If they get late I get worried, I wonder if they've had an accident. When I hear them opening the door I get happier.

(Brito, 2018: 32)

Service users shared knowledge, teaching languages and cooking, and in several instances service providers expressed frustration that they did not have the opportunity to learn more from care users. However, they could also make visible the invisible work of the care worker. In the same way that service providers must make themselves invisible to facilitate 'self-determination', it is also sometimes necessary to make this invisibility visible. This is effectively the work that Anna does through her appreciation of the effort/sacrifice entailed in staying in a stranger's house: 'She gave thought about what it took for a caregiver to leave her home behind and suddenly spend days and nights in a stranger's house, occupy an unknown space and [...] perform tasks that one usually would do at home'.

Managing these relationships is particularly difficult for those who live in, as is evident in several of the examples in the Turkish study. Magnuli from Georgia cares for Hilmi who is 96 years old and widowed seven years ago. He has loved ones who visit him regularly, but Magnuli cooks, does household chores and sits with him, as well as helping him to go to the toilet. She is described as being part of the family and she clearly has affection for Hilmi, but she also has children in Georgia. Her being considered part of Hilmi's family does not mean that her family members are related to his family members; indeed, it is the very fact that she is separated from her family that enables her to be 'part' of his. She misses her family and wants to retire and return to Georgia but Hilmi is desperate for her to stay. Thus it is not only the care worker who is rendered vulnerable in these relationships.

How to manage connections can also be challenging between family members and those they care for. Veres thus describes the feelings of Aron, a young man with cerebral palsy:

He was aware and tormented by the porosity of roles his mother embodied. When she was giving him a lift, was she his mother or his carer? Could he stay silent and think his thoughts or was this the only time during the day when mother and son met and when they could talk a bit about their days?

(Veres, 2018: 32)

One reason given by service users for the preference for commodified care is that conflict can be easier to manage than it is with family members: '[My brother] is allowed to be angry at me, because he is my brother [...] but as an employee he isn't allowed to be angry at me, because I am feeding the account' (Meier, 2018: 33-34). This does not mean that service users find conflict unproblematic in this situation of interdependence and intimacy: 'I don't want to hurt people and often don't say anything if I am not happy with something' (Meier, 2018: 51). However, it is much easier to terminate a relationship with a (former) employee than with a family member, and several of the Turkish families had terminated the contracts of previous care workers because of dissatisfaction. The advantage of commodification in the management of conflict may be experienced more negatively by the service provider who may be conscious of the need to keep silent: 'What's not so good is you need to be able to hold back, to hold yourself back very well, and in many issues that's [...] difficult sometimes' (Meier, 2018: 30-31). The conflicts described were usually over very small matters: what to do with unused egg whites or service users calling relatives too often during the day. They were not conflicts over matters of justice, but rather everyday petty disagreements. The tension between family members and care workers can be more difficult to manage, as Brito describes in the Portuguese study. She describes situations where care workers could feel unprotected from family demands, criticisms and queries by the institution that employs them (Brito, 2018: 41). More generally the vexed question of who to make claims against – the municipality, the government, the institution or private company providing the care – means that the care worker is the only one in line.

Meier notes that most of the Austrian studies of personal assistance put the relationship between the personal assistant and the employer at the centre of research (Meier, 2018: 12). This seems paradoxical at a time where such strong efforts are made to de-personalise the relationship. In the case of personal assistance the connection is managed through an unwavering insistence on contractualisation. This is not easy. The connections that all parties are seeking to manage are imbricated with emotion and power. Contractualisation seeks to affirm the connection but to sanitise it of these associations. Thus, the relations described in the Austrian case study are attempts to instrumentalise the labour of people and separate it from any emotional content, but this is extremely difficult in relation to intimate body work, particularly when it is conducted in the private household. As well as the language of 'family' care users can also claim that care workers, like personal assistants, are body parts:

'Remziye is my eye when I am watching TV, my hand when I am cooking and my arm when I am working', Didar says. She says that Remziye's left arm belongs to her, because she grasps it for support as she moves from room to room.

(Akkan and Serim, 2018: 18)

One of the cases described by the Austrian study is a young woman with cerebral palsy. She is assessed as demonstrating 'difficulties in adopting a clear leadership role' (Meier, 2018: 51), evidenced by her ambivalence in

her management of her relationships with her personal assistants: 'Is it nice that the person feels so close to me, or is it too much if they borrow my socks or sit on my bed [...] Then I think it does overstep the boundaries a little' (Meier, 2018: 51). Furthermore, this contractualisation is not easy to maintain. Even CS did not extend his support for contractualised relations to support for personal assistants joining a trades union. He claimed, but could not argue, that this kind of regularisation would be negative for personal assistants and that the voucher system under which personal assistants were employed offered sufficient protection.

The alternative to the contractual 'story' of equal relations freely entered into is the familial story of responsibility and care, but this too has problems. Families are woven into uneven sets of patriarchal obligations to each other and while carers are also woven into obligations, these are usually far more tenuous and less resilient than kinship, however tough they seem. Care workers can be dismissed far more easily than family members. In addition, the more like a family member, the less like a worker, and justice claims for wages, reasonable working hours and conditions are claims of workers. On the other hand, the more like a worker the more alienated and instrumentalised the labour, and as many of the care workers in the national case studies aver, it is the relationality of care that gives them pleasure in their work and makes them feel their contribution is recognised. While policy is very much focussed on the needs of care users (and in some states their families), there is also some attention paid to the rights of care workers. Nevertheless, little attention is paid to the need of care workers to give quality care as part of a life they have reason to value. They wanted to be able to give 'warm care' (Knijn and Hiah, 2018: 42) as part of giving value to their lives. Furthermore, as with other service sector work, to do care well, you must enjoy it, or at least be perceived as enjoying it, not just doing it as a job to be done: 'You should be in love with your job. Sometimes, you can find yourself in difficult situations [...] At these points you must have passion to do your work, and you must show a kind of devotion, otherwise you cannot do this job.'

What do all these complex connections mean for Capability Theory? Several of Nussbaum's central human functionings seem to reflect what is missing or being demanded in the national case studies because it gives us a vocabulary to legitimate these claims outside the family context. For example, both care users and care workers demonstrate the urge for affiliation 'to show concern for other human beings, to engage in various forms of social interaction'. However, *contra* Nussbaum participants are not starting from a position of separation from which they are seeking connection and relationality. They are seeking not to *make* but to *manage* connections, whether by contract and rules, professional distance, particular use of space, depicting people as family members and so on. There is not a single correct kind of connection, but it is important to service users, providers and family members that they have the right kind of connection, and that all parties share an understanding of what that connection is. To return to our two case studies, Antonio is connected to his sister, who he would like to live with him, and to the care workers, whom he worries about and wishes to spend more time with. He wants to change the character of these connections. CS is also connected to his partner and children, with whom he seeks a relation unmediated by 'professionals', and to personal assistants, whose relationship must be closely managed in order to maintain his self-determination.

These connections can leave care workers open to 'moral distress'. 'Moral distress' is experienced when a person feels that they know the ethically right action to take or to enable, but they are institutionally or systematically prevented from doing it:

I don't like when we leave and we know that they aren't alright [...] Like when they are sick or in pain [...] We have 'our hearts in our hands, not know what to do but we know we cannot stay there, right? It's not our job, we don't go there for that.

(Brito, 2018: 26)

In order to manage moral distress, workers have to cut off from their emotional responses and turn their heart 'into stone' (Brito, 2018: 25). Moral distress has been well documented in the nursing literature and it has been found to be gendered, with female critical care nurses experiencing statistically significantly higher levels of moral distress than male critical care nurses for instance (O'Connell 2015) – though it may be too that men downplay experiences of distress because of gendered expectations (Monrouxe et al, 2015). One might read moral distress as an emotional experience of injustice on behalf of another person who is facing some kind of institutional blockage, where the person experiencing the distress is associated with the institution that is doing the blocking. Rather than emotional distress being a personal response that needs to be managed, it could be taken as an indication of a central capability for affiliation that is not being fulfilled.

Moral distress can also be read as one of the indications of what Nancy Fraser has called the massive pressures on social reproduction, what Fraser has called the 'smouldering flashpoint' of the capitalist crisis. In the national reports the consequences of welfare state retrenchment and increasing precarity are both observed and directly lived by women, with consequences for their emotional lives and development. Selma, a Dutch care worker for example, observes:

Before Dutch culture 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.

Knijin and Hiah, 2018

While there may be an element of nostalgia in our memories of a better past, this should not distract us from the ways in which she captures the new pressures on women caused by multiple fractures in social relationships, with significant consequences for those who provide care in families. And there are consequences too for paid care workers and personal assistants. For example, Mary, one of the users of personal assistants in the Austrian national study, noted that the personal budget model of employment lacked workers' protection. It is not only that the wages are too low, but it does not offer pregnancy/maternity pay, meaning that those who want to have families will often leave this kind of work. Moreover, she needs assistance at the very time when young children also do, 'in the morning to get up and receive bodily care, at noon to eat, and in the evening when going to bed'. It is important to note that this perceived incompatibility is not inevitable, and that some participants (including Selma) actively chose to work in the sector because it was easier to combine with childcare. Rather the point is that the reproduction of human communities and sustainable social relationships is under extreme pressure, and that this is particularly evident in those providing formal and informal care or personal assistance, who are largely women.

6) Capabilities, Temporalities and Process

Time

Caregivers' passion for their work is manifest in process. Process is about emotion and particular forms of connection, and it is important to the distinction between 'caring about' and 'caring for'. Process has the possibility to change work in a way that facilitates Sen's 'basic capabilities', to facilitate a life that one has reason to value. For example, having a clean body matters, but whether it is cleaned with soap that one likes or with a sense of respect for one's body or privacy may be equally important. Consider how Lina, a live-in care worker, feeds Ayca, an elderly woman she looks after: 'Ayca could not eat her meals on her own. This is a fun game for them. When Lina feeds Ayca she plays games [...]. She motivates her to eat through these games [...]. "My dear, please eat"' (Akkan and Serim, 2018: 17). Or the difference in caring style and relationship between Barbara, who makes coffee for Adrienne in the morning, and Moniek, who leaves her to brew it herself. One concerned with working 'systematically', the other with encouraging self-reliance. The outcome is the same, coffee, but the process is different. Process can turn the enablement of basic functionings into Nussbaum's 'affiliation'. But the converse may also be the case. For example, diapers are provided in the Portuguese care home so that care users do not soil their clothes, and in this sense their basic functionings are catered for. Susana is perfectly capable of using the toilet but needs assistance to get there. She often has to use a diaper because the care workers do not have the time to accompany her to the bathroom, and she finds this 'humiliating and unpleasant'. Basic capabilities are imagined by both Nussbaum and Sen as foundational to advanced capabilities, but a temporal lens on the national case studies suggests that the relation between conversion factors, capability sets and *process* merits attention.

Attention to process draws attention again to the importance of relationality and emotions. Emotions develop over time and there are attempts to obviate this, so timetables for paid care workers can be drawn up specifically to avoid too strong an attachment to particular individuals for example. Governing by rules can also help mitigate the development of attachment as is evident with CS2. Time key to the subjection of relational processes to contract as it measures or counts time, and gender plays a key role in experiences in relation to all these factors (time, relational processes and contract), and knits them together. Gender and temporality are entangled both in terms of life course and everyday life. For care workers like Maria and Ana, their work involves staying alongside others when other social relations have failed, it is a type of work that is bound up with what Simone de Beauvoir conceptualized as 'female waiting time'. It is a long-term commitment that is productive of emotional relations. This kind of time is fragmented and managed through enforcement of contract.

Furthermore, the resource input in support services is articulated as financial. The money that pays for care workers is, for states, the key resource that people are able in different ways to convert into capabilities that they can use to achieve functionings, beings and doings to attain a life that they have reason to value. However, our findings suggest that for the service providers and service users, even those who are handed direct budgets for care, the resource is *experienced* as time. This is not to say that care workers did not feel underpaid or exploited, but it is striking how much they described the consequences of lack of resources in terms of the suffering of their clients.

They [elderly care recipients] look forward to that half hour [of care]. But sometimes they [care workers] have to hurry so much that they don't even have the time to have a cup of coffee with a

person that just sits there, by herself [...]. Some things are unnecessary, but sometimes it would be good to grant them some more time in between the visits. Because that's what it's all about.

(Knijn and Hiah, 2018: 54)

The management of time and timetables is an importance aspect of care workers' responsibilities, and in the case of contractualised personal assistance service users are expected to develop duty rosters as part of their role as team leaders. Drawing clear borders between service hours and leisure time is also a way of escaping feelings of dependency on the part of the service user (Meier, 2018: 33-34) and preventing 'burn out' on the part of the service provider.

While the private is often thought of as a different space (eg the home), it also has very different temporalities. Moniek explicitly contrasts the temporalities of paid and unpaid care: in the latter case 'you can respect the patient's timing better' (Knijn and Hiah, 2018: 51). However, as paid carers whisk in and out of homes, there is a sense of institutional rhythms being imported into the private sphere, with service provision ordered and timetabled to accommodate multiple others. This is particularly noticeable when the limited and regimented time of care workers contrasts with the excessive time of care users. In some cases, their surfeit of time and lack of things to do means that they just go to bed. As Susana puts it, 'being here or not is kind of the same thing' (Brito, 2018: 37). Some care users complain about workers who make the time pressure explicit: 'When she comes she does things quick, quick and then she is gone [...]. She is always in a hurry, she says that this is because she has to go to another neighbourhood later on' (Knijn and Hiah, 2018: 46-47). The comparison is often made between good home care and more institutionalised care which is described as a 'factory line'. One participant contrasted the care he received at home with how he was treated when he was in hospital: 'Mr Jansen argues that it was assembly line work at the hospital. The patches and bandages are prepared in advance for the next patient' (Knijn and Hiah, 2018: 50).

In home care there are attempts to adjust schedules to clients, and in the Netherlands care workers had more flexibility in how they catered for care users' requirements than did the Portuguese care workers. This meant that they could for example decide to have a regular coffee break with Adrienne, which was important for the quality of the relationship (and therefore the care) that they gave her. But care workers also emphasised good use of time and stressed the importance of efficiency: 'You have to work efficiently because otherwise you will be out of time' (Knijn and Hiah, 2018: 39). Rather than industrial time we could think of this as 'contractual time', time measured out by contract and employment. Contractual time may also be associated with professionalism (Veres, 2018: 33). Thus contractual time for care workers may be experienced as a resource that can be measured and that has to be distributed *fairly* between multiple users: 'Of course we take the preferences into account as much as possible. But we have so many people and so many different preferences [...] and you cannot expect that someone can be helped every day at 8 o'clock' (Knijn and Hiah, 2018: 51). To be attentive care workers have to be sensitive to the needs of their clients, but it is through time that their clients are made aware of the fact that they are only one of many demands.

We don't have enough time [...] we wish that we could spend half an hour or even one hour with each one of them. But the houses are far apart, we lose a lot of time in the way and all of them need to have the same type of care. We cannot be more time with some of them and less with others (Brito, 2018: 23-24).

This is very different for (personally financed) live in workers where the borders of work and non-work are not demarcated on an hourly basis. In Turkey in particular, care workers sit, chat, watch television with the service user. They are able to devote themselves to the care user, getting to know their preferences and habits and adapting to their needs. The care users and their families clearly find this arrangement very satisfactory. These workers have very little time to themselves apart from their day off, and of the five commodified relationships examined in Turkey, only one caregiver had time to herself while in the house: "In other families, Simla never saw that the caregiver had ever spent time in her own room during the day [...] They always had some work to do. Even if they did not have chores to do they were sitting with the care users in the same room' (Akkan and Serim, 2018: 23). But the arrangements have a different rhythm. The care workers might have some grounds for demanding private space to sleep in and set rest hours but they seem rather to compensate for long and intense hours by returning to their countries of origin, sometimes for months at a time. Whether the long hours are experienced as injustice then in part could depend on the workers' temporal 'scale'.

This kind of management also has its temporal aspects, as we saw how it was its temporariness and its role in the life course of personal assistants that made it an acceptable arrangement for them. Temporary mindsets make a significant difference to one's responses and the kinds of claims one makes, and this is also the case for service users. In Hungary, Anna was paying for live in care workers as she recovered from illness. She found it difficult, as she 'favoured privacy and solitude', but the temporary nature of the arrangement meant that she could put up with the remedy that, in turn, was necessary for her to recover from illness. It also meant that she could cover it with her own savings, rather than rely on state support (which would have been insufficient). However, while Anna could be described as *tolerating* her situation, Antonio was being forced to *endure* his. This distinction between tolerance and endurance is in part whether one is orientated towards a better future or is trapped in a never-ending present. It suggests the importance of a dynamic analysis of the relation between resources, conversion factors and capability sets. Furthermore, we are all interdependent beings, but our dependence often becomes particularly visible at certain times in our lives. Temporally stretching our analysis complicates our ideas of reciprocity. As one care worker puts it, 'the reality of the elderly I care for will be my reality, my future' (Brito, 2018: 26). It is highly unlikely that the person that she is caring for now will directly reciprocate by providing her with (the resources for) care that she will need in the future, but the care worker is contributing to the 'web of care' (Tronto, 1993) that is woven within and across different societies and that may ultimately support her when she is in need.

Mobility

Temporal 'scale' can be related to mobility. In the ethnographies, those care workers who have moved long distances, whether from rural/small cities to large urban areas or across international borders like those workers described in the Turkish national study, are living in, and indeed their daily movements may be more restricted. Mobilities are related across people and scales. In order to enable what is often 'micro-mobilities' of service users, upstairs, into kitchens, out of beds within private households, personal assistants/care workers move between houses.

Mobility is a feature of discussions and illustrations of Capability Approaches and Theories and it appears in various guises in all the national studies. Control over one's mobility is strongly associated with freedom, and

relatedly with autonomy and independence. Mobility has an instrumental purpose and moving about the house in order to cook for oneself, for example, was supported by technologies and human presence in all the case studies:

(Adrienne's) home has been adjusted for her to be able to move around autonomously without a third person's help. Her front door can be electronically opened with a remote controller [...] She uses two different triple chairs to move around her home [...] and outside her home she uses a mobility scooter [...].

(Knijn and Hiah, 2018: 32)

Technological support is required by the care assistants who use bicycles, cars and airplanes to move to places of work, and by family members who can rely on cars to move their relatives from place to place. Movement, can, as we saw with Antonio, represent a form of escape and, particularly outside the house, it can also be undertaken for intrinsic pleasure:

Gul cannot walk well because of her leg problems and Meryem accompanies her when she goes to the toilet or when she moves from one room to another. They also go outside for a walk and meet with neighbours three times a week. First, they take a walk for thirty minutes and then they sit on the benches in the park with their neighbors.

The mutuality of our dependence and the overlapping of our capability sets can be illustrated through a mobility lens. Mobility is hampered or facilitated by public policy, whether it enables workers to support service users leaving the home (through time, insurance, delivery priorities etc) or promotes practices and designs that are apparently not linked to elderly or disability matters but in practice have significant impact on them. In the Hungarian national study for example, Aron, a young man with cerebral palsy, describes his difficulties using public transport:

The simple act of taking the tram and reaching the seat that was being offered to him [...] was a real challenge. The handholds did not help him [...] as their placement was not designed with disabled people in mind. Was it worth wading his way past a crowd of people and by the time he arrived there it was already time to get off? Or was it better to stand and spare himself the physical pain that moving meant?

(Veres, 2018: 30)

This brief description captures how able bodies are assumed as the norm, and people are thereby rendered disabled and more dependent on particular individuals (in Aron's case, on his mother, who has a car). Mobilities are also facilitated and restricted by networks. This has been explored in some depth by migration scholars (as migrants move internationally they may be helped by networks as well as remove themselves from networks) but it is also true at the micro scale, as networks of family carers help people to move so they can shop, attend weddings, and enjoy the fresh air.

All this suggests it might be fruitful to bring into conversation Capability Theory and the 'mobilities turn' in the social sciences. The mobilities turn highlighted the importance to the global economy of the intersection of everyday lives with mobility systems and promoted the new field of 'mobilities' (Hannam et al., 2006; Shelley and Urry, 2006; Urry, 2007). It aimed 'to develop through appropriate metaphors a sociology which focuses upon movement, mobility and contingent ordering, rather than upon stasis, structure and social order' (Urry, 2007: 18). The 'mobilities turn' linked different scales and forms of movement and promoted methodological moves away

from boundedness and the sedentary, recognising the ‘entanglement of movement with meaning and power’ (Cresswell, 2011: 553). It is this entanglement that connects it to issues of justice and fairness, and this becomes very visible in the national case studies. Mobility is a functioning but it is also a critical conversion factor that enables individuals to convert resources into capability sets. For those with mobility challenges attention may be focused on the individual conversion factors, that is, the nature of the person’s impairment, but as Aron’s description of the tram suggests, this is also a social impediment.

Mobility also refers to migration. As noted in the introduction, in Hungary and Turkey migration is an source of care labour. There are also many migrants working in Austria, though not under the personal assistance arrangements described in the ETHOS Austrian study, and while live-in migrant care givers are unusual in the Netherlands (approximately 200 according to Da Roit and Bochove 2017 (cited Knijn and Hiah 2018), some au pairs seem to be working in the eldercare sector. Work by investigative journalists has also uncovered informal and exploitative live-in migrant care worker markets, and Knijn and Hiah express concern that the demographic and labour market conditions are currently in place to exacerbate this. In Portugal too, while care work continues to be predominantly national women, there is evidence that non-nationals are increasingly working in the sector, particularly in urban areas (Brito 2018). It is worth noting that female care workers may be perceived as less of a ‘threat’ than male migrant workers and those working in other sectors, and therefore working in breach of stay and conditions more tolerated. This is certainly the case with au pair visa holders who often work extra hours and even take up additional jobs, without being perceived as ‘undocumented migrants’ (Anderson 2009)

It is important to note that the fact that a care worker is a ‘migrant’ does not mean that she is necessarily an ethnic minority (as in the Hungarian case for example). However, nationality and race are bound up with each other in very complicated ways such that, even if a person is phenotypically the same as the majority, accent, dress, religion or other features, may mark them as different and this may be captured as nationality. Furthermore, a person may be a citizen, but may not be the majority ethnicity. Selma, a Dutch care worker in the Netherlands, is of mixed Indonesian heritage, and described how her cultural background, presumably formed of her family relations, initially informed her work: ‘From the Indonesian cultural perspective it was difficult. I was used to taking a subordinate attitude towards the Indonesian elderly, but in my job I had to learn to say no... and that was difficult at first’ (Knijn and Hiah 2018). Notably she also asserts ‘I never heard anyone mention my ethnic background and I am not even aware that it matters to others in my job’.

7) Conclusion: Capability, Redistribution, Recognition, Representation

One of the tasks of this Deliverable was to see what light the application of Capability Approaches/Theory sheds on the relationships of commodified adult care in private homes. We have found that taking the Capability focus on a life one has good reason to value as a starting point can be incredibly fruitful. This is a question that, correctly and sensitively put, most people have the possibility of engaging with. It is also a question which will produce widely variant answers depending on the personal, social and institutional situation of the person one is asking. Taking the very different approaches of the Independent Living Movement on the one hand, and the vulnerability and care focus of elderly people on the other, it provides a language for both care recipients and users of personal assistants to make claims. However, it does raise the issue of how 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.

The second and related task was to see what attention to the relationships of commodified adult care in private homes reveals about Capability Approaches/Theory, in the context of ETHOS engagement with Fraser's theory of justice. While Nussbaum's emphasis on emotion and affiliation for the purposes of justice is very useful, the ethnographies suggest the limitations of having as a starting point the separated individual who has the right to connection as a point of justice. While it is the case that both elderly and disabled people complained about being overlooked, not recognised as valuable persons who have dignity and individuality, being spoken past or ignored if a wheelchair user. However, in practice the issues seem much more to relate to the management of connections that may be regarded as unsatisfactory. Indeed, the personal assistance model in Austria indicates that the idealised imagined autonomous and independent individual – in other words, disconnection – is in some cases the desired *end point*. Furthermore, these connections are gendered. We began by noting that CA can be useful in generating gender-sensitive analysis, and gender is also one of Fraser's preoccupations. What is striking about gender in the national reports is how it structures relationships and is assumed evident by care workers and care recipients alike. The ethnographies show the evidence of gendered female familial care as a priority care relation, sometimes also as a last resort, they also indicate the fragile labour relation of (migrant) care workers and how the gendering care work by its association with familiarity confuses relations of hierarchy and undermines respect and dignity. Moral commitment and moral distress take turn in these gendered care relations where women care workers feel that structural resources do not suffice to recognize the value of their work nor the needs of the people they care for. The fact that both 'family' and 'home' care, whether paid or unpaid, is predominantly female seems to be taken for granted. Precisely because of its obviousness, the gendered nature of affiliation, emotion and interdependence thus remains an unspoken assumption.

Both Fraser and Capability Approaches are concerned with the limitations of purely redistributive approaches to justice. They argue that people differ in their (embodied) conversion factors that enable them to convert resources into capability sets. This does not mean that redistributive justice can be ignored. In all the national studies those with higher income were able to bypass obstructions to the formation of decent capability sets. The Hungarian study found that class position and profession 'cushioned' participants from the worst effects of state disinterest and dismissal, while in Portugal institutional care workers joked about the fact that the residents of the more expensive 'New Wing' were bathed more often than those of the 'Old Wing': 'Maybe it's because they pay more, they have the right to use more soap' (Brito, 2018: 41). These resources are not only about income however and include family networks. The review of Dutch literature for instance found that 'the main discriminatory difference is that more highly educated people with more communicative skills seem better able to get access to the care service, regardless of their income' (Da Roit and Thomese, 2017, cited in Knijn and Hiah, 2018: 15). Navigating often complex bureaucracies can enable those who are confident, or well educated to gain resources that are not immediately accessible. Furthermore, if those with human, social and financial capital can escape social impediments it diminishes overall capacity to protest at these impediments, so that frustration is vented in private

rather than through public protest. In Hungary most of those claiming the care allowance are middle-aged women who have cared for their seriously disabled children for decades. The fact that this is set at one third of the minimum wage and that health insurance only covers a limited period of illness raises serious questions of gender and redistributive justice. Aron's mother, who devotedly cared for him all his life, did not know about the scheme:

Their reaction was one of amazement and amusement. When I later spoke again to Aron, he confided that they had talked about this and they were making jokes at the thought of him paying his mother with state money for caring for him. The idea that his mother caring for him could be remunerated seemed to them quite bizarre.

(Veres, 2018: 30)

Both were supportive of the claims of protesters but very removed from their realities.

Redistributive justice is also at issue for care workers. It is not simply that workers are poorly paid but that they also carry serious responsibilities, indicating these responsibilities are not properly recognised (Knijn and Hiah, 2018: 54). Both service users and providers sought respect from each other, and for the providers this could also be expressed as a desire for appreciation. Appreciation/recognition is particularly important in a context where wages are low and the work is given little status: 'In business [...] you get a certificate at some point or whatever then you will also be paid for it [...] but that is not really the case with us' (Knijn and Hiah, 2018: 35). Care workers, in turn, recognised care users.

This mutuality of recognition is often expressed in terms of 'good communication', which it is claimed can help anticipate or resolve conflicts. Knijn and Hiah emphasise 'recognitive justice', referring to people feeling they have been fairly and appropriately dealt with: 'Interactional justice is a two-way process of mutual respect: not only the care worker but also the care recipients appreciate being treated in a respectful way. Transparency and open communication are part of that process' (Knijn and Hiah, 2018: 56). However, communication, even good communication, is not deliberation. Participation in deliberative processes for many care users was very limited. Indeed, some participants vocalised frustration at their lack of political representation: 'She had no say in what the state was doing, she had no voice that the state would listen to' (Veres, 2018: 24). Care workers in Portugal commented that those in care homes had not been given the opportunity to vote in the general elections. The lack of voice and representation contributed to pressures on care workers to 'represent' people they care for, but the low status given to their role meant that their possibilities were limited. They could affect individual change by personal contacts (as Barbara managed to find a free holiday place for Adrienne) but structural change, or even change in the institutions they work for, seemed out of reach.

We find that redistribution, representation and recognition are powerfully but implicitly gendered through the distinction between the contractual and the familial which in turn is related to the liberal public/private distinction. Nussbaum acknowledges, CA/CT does not escape the problems associated with this divide – 'the language of capabilities does not automatically guarantee a critique of this baneful distinction' (Nussbaum 2011:32), but it can help identify the claims that Antonio is making in his dealings with Maria and Ana and offer a vocabulary to legitimate certain claims outside the family context, particularly the claim to affiliation - both care users and care workers demonstrate the urge 'to show concern for other human beings, to engage in various forms of social interaction'. While emotion and affiliation tend to be more associated with the private, for care workers like Maria and Ana they are also part of their working lives. They complained about workload, hours, lack of support and the

unhelpfulness of the institutional mechanisms within which they were working, but the ‘problem’ that really preoccupied them during the ethnographic research was Antonio’s situation and their involvement in his life: ‘We have our “hearts in our hands”, not knowing what to do, but we know we cannot stay there, right? It’s not our job, we don’t go there for that’. This kind of connection was not only a burden but also a source of satisfaction. Many of these workers clearly felt deeply that for them a life that is valued was one where one’s work is not only to do with earning an income but supporting people – that is, caring was an end in itself. While care work/personal assistance is a resource, care work, if not personal assistance, was also a functioning. They felt that being attentive to needs, getting to know people, was both demanded by the job and part of its worth. Thus, Maria and Ana felt that despite all their efforts they were not able to give the level of care that they would have liked, though the contrast between personal assistance and care work should not be taken for granted. As differences between service users are structured by policies, by gender personalities and by disability type, among other factors, so too personality, employment relations, gender life stage and other factors help shape the extent to which care assistants are emotionally invested in the longer-term lives of their clients, meaning people who work alongside each other can have very different attitudes to and interpretations of the relations under which they work.

The question remains however of how claims for improved capability sets can be raised and enforced, and in particular what are the mechanisms that can promote certain types of affective relations. Our findings raise a further question: how can these not reproduce gendered expectations and demands? In Nussbaum’s framework the state has the responsibility to promote core functional capabilities and it seems that the institutions of contract and family are inadequate to this task and indeed are structures through which gender relations are actively created and reinforced. In all country reports, we were struck by the invisibility of gender, and the fact that participants, whether workers or users of personal assistance or carers or family members, did not comment on the highly gendered nature of care provision, both formal and informal. It seems that family and contract function as institutional mechanism for invisibilising state implication in gender relations, and one important step forward could be to open accessible, practical and non-academic conversations that engage with how contract is gendered.

Recommendations

For national governments and NGOs:

- Bring together the theoretical, policy and practical insights gained from the experience of those who are disabled throughout their lives and those who become disabled later in life.
- Policymakers, civil society organisations and other stakeholders should clarify the meaning of ‘independence’ as an aim to be pursued in relation to family members, friends and local community. They should also acknowledge and problematise the gendered nature of ‘family support’, care work and personal assistance.
- Resources should be deployed to recognise the capacity of care users to be caregivers in practice.
- By default, disabled people should continue to receive the services they have always received as they reach retirement age. There should be studies on how these services are framed and modelled when delivered to older people.
- Participation, representation and deliberation are important in guiding people’s orientation to their social environment and their responses to felt injustices. People should be educated in how these differ from and relate to each other, and the role of institutions and officials in relation to each.

- Develop responses to 'moral distress' that go beyond the expectation that individual healthcare assistants or care workers must always simply manage it. Provide care workers with ethical training.
- There should be a limitation on the number of times temporary contracts (service vouchers, zero hour contracts) that can be renewed and still be classed as 'temporary'.

Bibliography

- Akkan, B. and Serim, S. (2018) *Commodified Care Relations: Elderly People with Disabilities and Migrant Care Workers in Turkey*, ETHOS WP 5.3, available from https://www.ethos-europe.eu/sites/default/files/5.3_turkey.pdf.
- Anderson, B. and Dupont, P. (2018) 'How Does it Feel to Be a Problem?' What We Can Learn About Justice as Political Representation from Empirical Case Studies, ETHOS Deliverable 5.2, available from https://www.ethos-europe.eu/sites/default/files//docs/d5.2_loaded_website_version.pdf.
- Anderson, B. (2009) "'What's in a name?'" Immigration controls and subjectivities: the case of au pair and domestic worker visa holders in the UK', *Subjectivity* 29: 407-424
- Benhabib, S. (1996) *Democracy and Difference: Contesting the Boundaries of the Political*, Princeton: Princeton University Press.
- Bonvin, J-M. and Laruffa, F. (2018) Deliberative Democracy in the Real World: The Contribution of the Capability Approach, *International Review of Sociology* 28(2): 1-18.
- Brito, L. (2018) *Being Paid to Care For or Care About? National Report - Portugal*, ETHOS WP 5.3, available from https://www.ethos-europe.eu/sites/default/files/5.3_portugal.pdf.
- Creswell, T. (2011) 'Mobilities I: Catching Up', *Progress in Human Geography* 35(4): 550-558.
- Daly, M. and Lewis, J. (2018) 'Conceptualising social care in the context of welfare state restructuring' in Lewis, J. (ed.) *Gender, social care and welfare state restructuring in Europe*.
- Dean, H. (2009) 'Critiquing Capabilities: The Distractions of a Beguiling Concept', *Critical Social Policy* 29(2), 261-278.
- Erman, E. (2012) 'In Search of Democratic Agency in Deliberative Governance', *European Journal of International Relations* 19(4): 847-868.
- Fields, D. and Kafai, Y. (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.
- Fraser, N. (2005) 'Mapping the Feminist Imagination: From Redistribution to Recognition to Representation', *Constellations* 12(3): 295-307.
- Fraser, N. (1998) 'From Redistribution to Recognition? Dilemmas of Justice in a "Post-Socialist" Age', in Willett, Cynthia (ed), *Theorizing Multiculturalism: A Guide to the Current Debate*, Malden, Massachusetts: John Wiley & Sons, 19-49.
- Gellert, P. and Feldman, S. (2006) 'The Seductive Quality of Central Human Capabilities: Sociological Insights into Nussbaum's and Sen's Disagreement', *Economy and Society* 35(3): 423-452.
- Knijin, G. and Hiah, J. (2018) *Competing Claims of Justice in the Private Household: The Dutch Case*, ETHOS WP 5.3, available from https://www.ethos-europe.eu/sites/default/files/5.3_netherlands.pdf.

- Meier, I. (2018) 'You Really Need to Hold Back, You Are Only the Surrogate Eye.' *Personal Assistance in Austria*, ETHOS WP 5.3, available from https://www.ethos-europe.eu/sites/default/files/5.3_austria.pdf.
- Mitra, S. (2006) The Capability Approach and Disability, *Journal of Disability Policy Studies* 16(4): 237-247.
- Monrouxe, L., Rees, C.E., Dennis, I. and Wells, S. (2015) 'Professionalism dilemmas, moral distress and the healthcare student: insights from two online UK-wide questionnaire studies. *BMJ Open* 5(5)
- Norwich, B. (2014) 'How Does the Capability Approach Address Current Issues in Special Educational Needs, Disability and Inclusive Education Field?', *Journal of Research in Special Educational Needs* 14(1): 16-21.
- Nussbaum, N. (2003) Capabilities as Fundamental Entitlements: Sen and Social Justice, *Feminist Economics* 9(2/3): 33-59.
- O'Connell, C. (2015) 'Gender and the Experience of Moral Distress in Critical Care Nurses', *Nursing Ethics* 22(1): 32-42.
- Rippon, S., Theuns T., de Maagt, S., Zala, M. and van den Brink, B. (2018) *Report on the European Heritage of Philosophical Theorizing about Justice*, ETHOS Deliverable 2.1, available from https://www.ethos-europe.eu/sites/default/files//docs/d2.1_website_report_complete.pdf.
- Robeyns, I. (2003) 'Is Nancy's Fraser's Critique of Theories of Distributive Justice Justified?' *Constellations* 10(4): 538-554.
- Sen, A. (2004) 'Capabilities, Lists and Public Reasons: Continuing the Conversation', *Feminist Economics* 10(3): 77-80.
- Sen, A. (1999) *Development as Freedom*, New York: Knopf.
- Sen, A. (1985) 'Well-being, Agency and Freedom: The Dewey Lectures 1984', *Journal of Philosophy* 82(4): 169-221.
- Terzi, L. (2010) *Justice and Equality in Education: A Capability Perspective on Disability and Special Educational Needs*, London: Bloomsbury.
- Terzi, L. (2005) 'Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Educational Needs', *Journal of Philosophy of Education* 39(3): 443-459.
- Trani, J-P, Bakhshi, P., Bellanca, N., Biggeri, M. and Marchetta, F. (2011) 'Disabilities through the Capability Approach Lens: Implications for Public Policies', *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap* 5(3): 143-157.
- Tronto, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, New York: Routledge.
- Urry, J. (2000). 'Mobile Sociology', *The British Journal of Sociology* 51(1): 185-203.
- Urry, J. (2007). *Mobilities*, Cambridge: Polity.
- Van den Brink, B., Rippon, S., Theuns. T. and Zala, M. (2018) *Report on the Workshop "Ideal and Non-Ideal Theories of Justice": Towards a Non-Ideal Theory of Justice in Europe*, ETHOS Deliverable 2.2, available from https://www.ethos-europe.eu/sites/default/files/docs/d2.1_website_report_complete.pdf.
- Veres, J. (2018). *Left Out in the Cold. Informal Home Care in Hungary*. ETHOS WP 5.3, available from https://www.ethos-europe.eu/sites/default/files/5.3_hungary.pdf.

Appendix One: D5.3 Case Study Protocol

Ethnography of physically disabled care users and paid care workers in private households

Objectives WP5: Justice as lived experience

Work package 5 is concerned with justice as lived experience. It examines the subjective experiences of those vulnerable to injustice in three spheres of justice: political, economic and social, and has a particular focus on people's lived experiences as members of ethnic and religious minorities, and as vulnerable categories in the welfare state such as disabled adults and care workers. The welfare state is pictured as a means of inclusion (access to welfare state provisions is a fundamental benefit of national citizenship) and of exclusion. We are interested in the conflicts, tensions and contradictions between different justice claims of vulnerable groups and how these are negotiated in the day to day. While it takes the perspective of the vulnerable, it avoids a focus on victimhood, emphasising agency.

Objectives D5.3

D5.3 explores the accommodation of justice claims in the lives of adult physically disabled care users (NB this can include older people) and people who are paid to provide care in private households with attention to the role of gender and, where appropriate and possible, ethnicity. We are interested in everyday practices of recognition and redistribution and how daily conflicts of justice claims are understood and managed (or not). Analysis will draw on a capability approach, considering people's capacity to achieve the kinds of lives that they value, and the achievements themselves. (See <http://www.iep.utm.edu/sen-cap/>).

Each partner (except the coordinators) will conduct a case study of five commodified care relationships supplemented by in-depth interviews to examine experiences of (in)justice by care users, those providing care and close relatives. These case studies will enable us to:

- Identify the intersections and contradictions between people's understandings, claims and experiences of recognition and redistribution;
- Identify the argumentative, practical and conceptual tools that people use to negotiate conflicting justice claims;
- Explore the contradictions and intersections between claims for and practices of justice;
- Explore the role of the state in creating conflicts and shared interests between care workers and care users (e.g. employment, immigration and taxation laws; support for the rights of disabled people and their carers; minimum care standards; cash for care arrangements; state engagement in private household);
- Analyse the specific challenges and opportunities for justice in the context of home-based care, and their link to ideas of the public and private spheres.

We will gather data on and analyse the justice claims of adult disabled care users, commodified care providers in private households, and employers of care workers (who may be home care agencies, family members i.e. not the

care user themselves). While there is a significant cross-national social policy literature on care provisions and arrangements and on the position of (migrant) care workers, very little studies have focused on the interaction between physically disabled adults and their care workers. Politically, both categories seem to vocal own particular interests, respectively care provisions accommodating independence or redistributive and claims for recognition. This does not mean that either group are inattentive to the rights of workers/disabled people in their personal practice, nor that it is impossible to formulate common interests (Folbre, 2006). However, on the face of it there are several possible conflicts of interests between care workers and care users. These include: difference of interests between workers and employers, such as living and working conditions, hours, rates of pay, holiday etc; differences around recognition as disabled adults, as ethnic minorities, as women; differences around immigration status and citizenship and how this plays out in particular commodified caring relationships. These differences can become both obfuscated and heightened when the person providing commodified care is also a family member paid under cash for care schemes, or when the professional care workers is tied to strict time schedules by the home care office she is employed by. Furthermore, as with other service sector work, the employment relationship may be 'triangular' in that the user of the service is not the employer, and the person paying for the service may have different ideas about the nature of the work and the relationship than the service user.

Employment in private households is often informal or has an informal element – additional hours and services not included in the contract for example. It is usually subject to particular exemptions from labour market standards and regulations – e.g. exemption from restrictions on working hours, minimum wage or health and safety protections. Workers may not be legally and/or socially constructed as employees, but as 'helpers', 'fictive kin' 'au pairs' etc (Grootegoed et al, 2009). They may also be 'real' kin under cash for care schemes. That is, it is a relationship whose commodification can produce unease, particularly when care work is involved – 'emotionally priceless and economically worthless' as Zelizer (add reference) puts it. Conversely it may also be highly professionalised and nurses too may work for private employers or home care agencies.

When it comes to immigration, in some countries it is a sector where undocumented workers can cluster. There are also often hierarchies of workers, with certain ethnic groups, religions, and nationalities deemed more desirable than others (often on the basis of highly racialised stereotypes). While women are in the majority, men also work in private homes (often particular 'feminised' nationalities). They may do work that is imagined as more masculine, like gardening, driving and washing windows, but they can also work in elder and disabled care because they are considered more capable of heavy lifting.

Elder and disabled care are differently commodified in different states (see Da Roit and Weicht, 2013); Luppi et al, 2018). We are interested in exploring how commodification shapes, constrains and facilitates claims for justice. Attention to the private household in particular will enable us to situate commodified care within the context of networks of interdependence that are not commodified, that is, how people who are paid to provide care interrelate with family members who also provide care but are not necessarily paid to do so. We will be able to explore, not only how the care provider and care user interact and negotiate differences but also how both interact with family members.

It seems that in all participating countries the state augments rather than replaces family care for disabled and older people. A common policy concern seems to be that those needing care should be able to remain in their home for as long as possible. Consequently families often end up arranging 'mixed care', whereby family members share care with paid carers.

Portugal: <http://www.socresonline.org.uk/17/4/1.html>;
https://sapiencia.ualg.pt/bitstream/10400.1/3621/1/kina21322ensfinal_soccare.pdf

Hungary: <https://link.springer.com/article/10.1007/s12062-012-9060-1>

Austria: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01049.x/full>

Netherlands: <https://www.cambridge.org/core/journals/ageing-and-society/article/care-revolutions-in-the-making-a-comparison-of-cash-for-care-programmes-in-four-european-countries/378696A430FCF4EE350256276B491E9B>

http://www.expertisecentrummantelzorg.nl/Site_EM/docs/pdf/Live-in-migrant-care-workers-in-the-Netherlands-Exploration-of-the-field.pdf

Turkey: <https://academic.oup.com/sp/article-abstract/21/1/103/1610900>

In particular the development of cash for care schemes in Hungary, Austria, Netherlands and Turkey raises important issues about independence and empowerment – and hence about recognition and redistribution and justice in caring relationships. <https://www.cambridge.org/core/journals/ageing-and-society/article/whose-empowerment-and-independence-a-crossnational-perspective-on-cash-for-care-schemes/81DD797FEC8C5C98DD803946530EA386>

Our sample

We have undertaken to study five commodified care relationships. This does not have to be five separate ethnographies but can be one network of five relationships (e.g. care user, three care workers, and the care workers' employer), or two networks (e.g. care user/employer A, care worker B; care user C, care worker B, employer D). While the care workers are likely to be migrant or from a minority ethnic group this is not a research requirement. We anticipate each ethnographic study will last for one week. We therefore expect between one and three weeks of fieldwork.

Access is likely to be challenging. To accommodate this we must be flexible in the nature of the care arrangements we are engaging with. The basic requirement is that it will generate data on *everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed (or not) in the context of the private household*. It will be up to the national teams to decide whether they are looking at live-in or live-out care workers.

It is important to emphasise that we are looking for examples of good practice, where relationships work and at least one party considers that different interests are successfully negotiated. We suggest that partners contact care agencies, self-organised groups of disabled people. Churches, mosques and other places of worship can also be useful sites for meeting migrant care workers and the people they care for.. Sometimes expensive care agencies are eager to demonstrate why they are better than the competition and can be more open than cheaper ones.

It is likely that you will have access to the care user/employer as the first point of contact, as the care worker will often not be in a position to facilitate access to the private home. It is therefore extremely important that the researcher is satisfied that employer, care user *and* worker have consented. Given the consent challenges we suggest that the care user is physically rather than mentally disabled. We take a broad understanding of care worker: if the person is expected to have physical or emotional contact with the care user then we understand this

to be care work. So for example, if a person is contracted to clean the house but is also expected to chat with the care user, we would include this as care work. Here it may be helpful to keep in mind the distinction Tronto (1987) makes between caring about (relational), caring for (organisational), taking care (the care activity itself) and being cared for (the care recipient).

Methodology

These relationships are likely to be complex and nuanced. While we are interested in discrepancies between claims, rights and acts, we are not trying to catch people out, but to reflect the complexity of these relationships. We have therefore chosen to use a combination of mini-ethnographies and semi-structured interviews. Ethnography is a useful method through which “to explore 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 & Kafai, 2009)” (see <http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2580&context=tqr>). It facilitates understandings of norms, values and roles and is a way to capture practices and what is unsaid. It is therefore particularly useful in researching relationships and nonverbal communication. Ethnographies can last years and involve immersion into a world of practices that the researcher must familiarise themselves with, however, mini-ethnographies are much shorter and can incorporate focussed field visits rather than embedding. In a European context, embedding in a private household is likely to be regarded as intrusive and would raise financial and resource issues, moreover, it is likely to have a significant impact on the relationship we are interested in observing. Furthermore, conducting ethnographies will enable us to compare different relationships facilitating an analysis of the private households as a specific site of justice. It is anticipated that researchers will not ‘live-in’ but will visit the households daily for a week and take part in activities with the worker and the care user as appropriate.

The semi-structured interviews will ‘bookend’ the mini-ethnographies.

Phase 1: Preparation for the field

It is important that partners understand the legal rights of care workers and disabled people before going into the field. This is also necessary for the design of research instruments. All partners will begin by producing a short report on law and policy on care and private households in their country. This will include labour rights of professional care workers and care workers paid by cash-for-care schemes, the rights of disabled people to care, labour rights in private households and, if migration is an important source of care labour, how migrants (including au pairs in some cases) fit into this picture. This report should also provide basic, easily available statistics on numbers of elder care, elder and disabled care providers in private households and, if possible, the demographics of care workers. It does not have to be fully written up – bullet points will do. We will also ask for a ‘map’ of the commodified relationships you will be exploring, eg my ethnography will comprise care user/employer A, care worker B; family member C and D, part-time care worker E. On the basis of this information the WP co-ordinators will work with you to draft interview schedules.

Please note that ethical procedures may be cumbersome, and you will need to initiate the process as soon as possible.

Phase 2: Interviews and ethnographic work

The first semi-structured interview will be conducted before the ethnographic work commences and will be based on interview schedules designed by the co-ordinators in conjunction with country investigators. Interviews will be conducted separately with care workers, care users, care agencies and, if appropriate, family members, one of whom may be the employer. They will cover factual questions about demographic indicators (age, education, income and ethnicity), care users history of care needs and the way it has been provided, care workers history of employment and family members history of caring for their relative, their understandings of justice with respect to disability and employment relations, and how they negotiate daily care arrangements with the care worker/care user.

The co-ordinators will circulate a draft template for fieldnotes.

The second interview will be conducted after the ethnographic work and will be 'bespoke' and designed by the ethnographer/WP lead in communication with the WP5 co-ordinators. It might be that national teams decide they will prefer to conduct a focus group discussion with care workers, and a focus group discussion with care workers. This can be decided after ethnographic fieldwork.

Phase 3: Analysis

We suggest that national teams use NVivo for analysis. Coding frames will follow the questions of the research and will be open to unexpected findings.

Time frame (2018)

Phase 1 Feb- March

February

- Ethnographers receive training in Coimbra.
- Partners initiate ethical procedure for ethnographies and interviews.

March

- Partners produce research brief covering 'map' of commodified relationships (see above), legal rights, basic statistics if easily available, and key readings on commodified care relationships in private households in their countries.
- 26 March: Voluntary Skype discussion for partners to ask questions on research brief. Partners must send request by 22 March.

Phase 2 April- June

April

- April 2nd partners send research brief including map and legal rights
- Week of 2nd April WP5 coordinators work with partners to produce interview schedules.
- April 9th coordinators circulate interview schedules and fieldwork note template to all partners

- April 10th 11am UK time: Skype interview to discuss and finalise fieldwork template
- April 13th partners confirm fieldwork dates.
- April 16th coordinators circulate national report templates to all partners and schedule for fieldwork Skypes to share ideas and discuss second interviews.

May-June

- Partners prepare and conduct mini-ethnographies (NB data recording to be done at same time as fieldwork)
- June 11th Skype discussion for partners to give verbal feedback on their findings
- June 18th Skype discussion on coding frames

July - August

- Report writing
- August 6th partners hand in national reports

Suggested readings

ANDERSON, Bridget and SHUTES, Isabel. (2014). "Conclusion". In *Migration and care labour: Theory, policy and politics*. London: Palgrave Macmillan, pp. 213-225.

BARNES, Marian. (2012). *Care in everyday life: An ethic of care in practice*. Bristol: Policy Press, pp. 61-85 [working at care].

FOLBRE, Nancy, 2006, Demanding Quality: Worker/Consumer Coalitions and "High Road" Strategies in the Care Sector, *Politics & Society*, 34 (1), pp. 11-32.

GROOTEGOED, E., T. KNIJN and B. DA ROIT, 2010, 'Relatives as paid care-givers: how family carers experience payments for care', *Ageing & Society* 30 (3), pp. 467-489

KNIJN, T. & C. Ungerson, 1997, 'Introduction: Care, Work and Gender in Welfare Regimes'. *Social Politics. International Studies in Gender, State and Society*, 4 (3), pp. 323-327

KNIJN, T. & M. Kremer, 1997, 'Gender and the caring dimension of welfare states: toward inclusive citizenship'. *Social Politics. International Studies in Gender, State and Society*, 4 (3), pp. 328-361.

KNIJN, Trudie and VERHAGEN, Stijn (2007), "Contested professionalism: Payments for care and the quality of home care", *Administration & Society* 39(4), pp. 451-475.

LUPPI, Matteo, Rosanne OOMKENS, Trudie KNIJN and Bernhard WEICHT, (2015) *Citizenship in the context of migrant care work. Regimes, Rights & Recognition*, bEUcitizen Deliverable 9.6, Utrecht University, 18-07-2015.

NAKANO GLENN, Evelyn. (2010). *Forced to care: Coercion and caregiving in America*. Cambridge: Harvard University Press, pp. 1-11 [introduction].

STONE, Deborah. (2000). "Caring by the book". In HARRINGTON MEYER, Madonna, *Care work: Gender, labor and the welfare state*, London: Routledge, pp. 89-111.

TRAUSTADÓTTIR, Rannveig. (2000). "Disability reform and women's caring work". In HARRINGTON MEYER, Madonna, *Care work: Gender, labor and the welfare state*, London: Routledge, pp. 249-269.

Appendix Two: Methodological Note to Accompany National Case Studies

Objectives D5.3

D5.3 explores the accommodation of justice claims in the lives of adult physically disabled care users and care workers in private households. We are interested in everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed (or not). Analysis will draw on a capability approach, considering people's capacity to achieve the kinds of lives that they value, and the achievements themselves. (See <http://www.iep.utm.edu/sen-cap/>).

Each national case study was designed to enable us to:

- Identify the intersections and contradictions between people's understandings, claims and experiences of recognition and redistribution;
- Identify the argumentative, practical and conceptual tools that people use to negotiate conflicting justice claims;
- Explore the contradictions and intersections between claims for and practices of justice;
- Explore the role of the national state in creating conflicts and shared interests between care workers and care users (e.g. employment, immigration and taxation laws; support for the rights of disabled people and their carers; minimum care standards; engagement in private household);
- Analyse the specific challenges and opportunities for justice in the context of the private Analyse the specific challenges and opportunities for justice in the context of home-based care, and their link to ideas of the public and private spheres.

Fieldwork Preparation

All partners began by producing a short report on law and policy on care and private households in their country. This included labour rights of professional care workers and care workers paid by cash-for-care schemes, the rights of disabled people to care, labour rights in private households and, if migration is an important source of care labour, how migrants (including au pairs in some cases) fit into this picture. This report also provided basic, easily available statistics on numbers of elder care, elder and disabled care providers in private households and, where possible, the demographics of care workers. They also provided a 'map' of the commodified relationships my ethnography will comprise care user/employer A, care worker B; family member C and D, part-time care worker E.

Because of the complexity and nuance of these relationships we used a combination of mini-ethnographies and semi-structured interviews. Ethnography is a useful method through which "to explore 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 & Kafai, 2009)" (see <http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2580&context=tqr>). It facilitates understandings of norms, values and roles and is a way to capture practices and what is unsaid. It is therefore particularly useful in researching relationships and nonverbal communication. Ethnographies can last years and involve immersion into a world of practices that the researcher must familiarise themselves with, however, mini-ethnographies are much shorter and can incorporate focussed field visits rather than embedding. In a European context, embedding in a private

household is likely to be regarded as intrusive and would raise financial and resource issues, moreover, it is likely to have a significant impact on the relationship we are interested in observing. Furthermore, we decided that conducting three, week-long ethnographies would enable us to compare different relationships facilitating an analysis of the private households as a specific site of justice. It was anticipated that researchers will not ‘live-in’ but will visit the households daily for a week and take part in activities with the worker and the care user as appropriate. Researchers were trained in the conduct and recording of research finding in a workshop during the ETHOS meeting in Coimbra (see Appendix One). They were also given readings to prepare for this (see Appendices One and Two).

Semi-structured interviews ‘bookended’ the mini-ethnographies. The first semi-structured interview was conducted before the ethnographic work commenced and was based on an interview schedule designed by the coordinators. Interviews were conducted separately with care workers and care users and will cover factual questions about people’s backgrounds and employment arrangements, their understandings of justice with respect to disability and employment relations, and how they negotiate with the care worker/care user (see Appendix Three).

Our sample

We were committed to studying five commodified care relationships, but explained that this did not have to be five separate ethnographies but could be one network of five relationships (e.g. care user, three care workers, and the care workers’ employer), or two networks (e.g. care user/employer A, care worker B; care user C, care worker B, employer D). This was largely because we knew that access was likely to be challenging. To accommodate this we were flexible in the nature of the care arrangements we are engaging with, but took as a basic requirement that it will generate data on *everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed (or not) in the context of the private household*. It was up to the national teams to decide whether they are looking at live-in or live-out care workers.

We emphasised that we were looking for examples of good practice, where relationships work and at least one party considers that different interests are successfully negotiated. We suggested that partners contact care agencies, self-organised groups of disabled people and that churches, mosques and other places of worship can also be useful sites for meeting migrant care workers and the people they care for.

Time frame (2018)

Phase 1 Feb- March

February

- Ethnographers receive training in Coimbra.
- Partners initiate ethical procedure for ethnographies and interviews.

March

- Partners produce research brief covering ‘map’ of commodified relationships (see above), legal rights, basic statistics if easily available, and key readings on commodified care relationships in private households in their countries.

- 26 March: Voluntary Skype discussion for partners to ask questions on research brief. Partners must send request by 22 March.

Phase 2 April- June

April

- April 2nd partners send research brief including map and legal rights
- Week of 2nd April WP5 coordinators work with partners to produce interview schedules.
- April 9th coordinators circulate interview schedules and fieldwork note template to all partners
- April 10th 11am UK time: Skype interview to discuss and finalise fieldwork template
- April 13th partners confirm fieldwork dates.
- April 16th coordinators circulate national report templates to all partners and schedule for fieldwork Skypes to share ideas and discuss second interviews.

May-June

- Partners prepare and conduct mini-ethnographies (NB data recording to be done at same time as fieldwork)
- June 11th Skype discussion for partners to give verbal feedback on their findings
- June 18th Skype discussion on coding frames

July - August

- Report writing
- August 6th partners hand in national reports.

Methodological overview per country

Access to conduct mini-ethnographies was challenging for all national teams, particularly in the time available. Given the very different cultural and institutional contexts we did not require studies to be directly comparable but rather were concerned to generate reports that would enable us to contribute to the theorising of justice by accessing felt experiences of injustice within the structural context that underpins them. Temporal constraints also meant we had to be flexible in our requirements. We did not insist on restricting the study to disabled people in youth and middle years but were open to the inclusion of people who had become disabled with age. Because of the potentially complex ethical issues involved we did not include people with cognitive impairments. We emphasised that we were interested in good relationships and that we were not trying to catch people out but to reflect the complexity of these relationships. Access to private homes for conducting the mini ethnographies was also challenging because people are hesitant to invite ‘outsiders’ in their homes and because we needed permission (Ethical consent) from a broader social network of persons and organisations involved. Nonetheless we succeeded in involving as many and as diverse care relations as wished in this study.

Methodology: Austria

We first drew on legal and policy documents to produce a short report on care and private households in Austria. This was used to develop the first part of our national case study. Fieldwork combined mini-ethnographies and semi-structured interviews with users and providers of personal assistance. The service users were interviewed twice: at the beginning of the mini-ethnographies, and several times after the visits. Both the semi-structural interviews as well as the field visits followed the guidelines developed by the project coordinators (see Appendix Three). These guidelines were translated into the national language and slightly adapted along the specific context and subject of personal assistance – which is understood in opposition to ‘care work’. Thus, personal assistance per concept implies self-determination (see section II on national context). Also the level of detail in the guidelines was adapted to the national context.

Access

The following strategies were applied to get access to the field: contacting individuals, who published job announcements for personal assistants. This strategy proved not successful. Later on, the Styrian Association “Selbstbestimmt Leben” was asked for support in access to the field. This association is an umbrella organisation of users of personal assistance. It was founded in 2012 for the purpose of representing the interests of persons with disabilities, particularly in the fields of inclusion and participation in society. The main tasks of this association are representing the interests of persons with disabilities before politics, public administration and the general public and supporting people with disabilities in applying for funds and services.

The executive board of this organisation was informed about the project, its embeddedness into the ETHOS project and Horizon 2020. Moreover, they were informed about the methods of data gathering, data evaluation and data protection. The board circulated the request for participation among their members. Many users expressed their interest in participating in the survey – the readiness was significantly higher than expected. The centre for integrated studies (Zentrum integriert Studieren) at the University of Graz was another successful channel for

recruiting cases. A member of this centre received the call for participation via the association Selbstbestimmt Leben and distributed it among their students. In the end, more people than needed expressed their readiness to participate in the survey. Interestingly, the majority of these persons were blind. All these persons highly valued the study and research. One blind person expressed interest in participating in the study but did not give consent to the visits in her home. She only wanted to share her views in the framework of an interview. However, unfortunately, this person and others had to be refused. Criteria for refusal were: order of consent for participation, location (persons, living in too remote areas were excluded) and heterogeneity of the sample (the aim was to include people with different kinds of disabilities and experiences with service provision).

Ethics

An application for an ethical approval was requested from the University of Graz before the fieldwork started. The application followed the standardised procedure implemented by the University of Graz, containing the following information: title of the research project, persons responsible, research disciplines, funding. A description of the research project, focusing on content of research, aims and objectives, interviewees, methods of recruiting and information on personal data gathered was added based on the research guidelines. Information on specific ethical issues included that there are no interest conflicts of all scientists involved and that there are neither advantages nor disadvantages for all research participants. It was clearly described that participation in research is voluntarily and can be withdrawn at any time until the report is published. The informed consent information letter and form was attached to the application. As this research project involves persons with disabilities, information was provided on how to obtain consent barrier free, i.e. reading it out and audiotaping verbal consent in case of blind persons. Finally, information on the protection of personal data was provided. The ethic committee approved this research project within a few weeks (application submitted on 26 March approval obtained on 19 April).

Sample

The sample consists of four users of personal assistance and five assistants. Three service users are blind, two are fully blind and one is partly blind. The fourth service user is spastic and uses an electronic wheelchair. One partly blind person and one fully blind person included in the sample live together and have three children, who are not disabled. The other two live alone. Three out of four service users are female. All service users are aged between 25 and 35 and all are employed in part-time, three out of four have obtained University degree.

For further details please see the national case study, available from https://www.ethos-europe.eu/sites/default/files/5.3_austria.pdf.

Methodology: Hungary

In order to contextualise the analysis, the researcher first mapped the Hungarian background through a review of the academic literature relevant to commodified home care in Hungary, a legal and policy analysis, and presentation of a selection of available national data. Fieldwork was conducted with two households between May and July 2018. It was comprised of daily home-visits, each approximately five-hours long, for between one week and ten days, complemented by semi-structured interviews with all the participants involved in the commodified care relationships. Two semi-structured interviews were also conducted with a mediating person, who, while not directly involved in these arrangements, was central in bringing them about. The interviews lasted between 20 minutes and

one and half hour. Some were conducted in the private households of the care users and others in public cafés. Ethnographic notes were taken, but no audio recordings, during the in-house visits. Every interview was audio recorded, transcribed, and carefully analysed.

Access

Securing access to the two private households was a long and mediated process. Access was based on trust networks, friendships and work relations that had existed well before the time of the fieldwork. The initial aim was to observe Transylvanian Hungarian carers. This is a Hungarian minority ethnic group who live in and are citizens of Romania, and whose mother tongue is Hungarian origin and who are major providers of private care in Hungary, along with ethnic Hungarians who are citizens of Ukraine and Serbia. The contact person although agreeing to help, after several attempts informed that her contacts were reluctant to participate because of its association with the CEU. (This was at the time leading up to the April 8th, 2018 national elections and CEU was under attack from the government).

Next, the Centre for Early Intervention was contacted, a service to support children aged six and under who have delayed or impaired development. It offers complex diagnostic assessment, individual and planned developmental and therapeutic programmes for children and their families. However, the only person the Centre suggested for participating was an active parent of an autistic child who felt outside the sample because ethical considerations required that fieldwork be conducted only with people with physical disabilities.

Via a personal contact who helps elderly Jewish Holocaust survivors to find appropriate care it became possible to find a first respondent. The second care relationship was accessed through a personal contact. The respondent was much curious as what a researcher would do. In both cases respondents openly stated that they were happy to take part in this research and thereby show their support of the CEU.

Ethics

This research has complied with all the ethical guidelines stipulated in the relevant documents, receiving permission to conduct it from the Central European University's Ethical Commission. All the names used here are pseudonyms and all the participants have consented to their participation in this study in writing.

Sample

The sample consists of two households. The first consists of an elderly frail woman, aged 93, 'Anna', and two female care givers, 'Maria' and 'Paula', both pensioners in their mid-sixties. Maria was from a town in Eastern Hungary, and Paula was from Budapest. They both lived in for 10 days at a time. The second is Aron, young man aged 25 (Aron), with a physical disability, a professional physical therapist - a former conductor, now working as a Shiatsu therapist, and the mother of the young man.

For further details please see the national case study, available from https://www.ethos-europe.eu/sites/default/files/5.3_hungary.pdf.

Methodology: The Netherlands

As a first stage in this work the researchers undertook a literature and policy review to present an overview of care workers' and care recipients' rights and obligations in the Netherlands. This later formed the basis of the first part

of the national report. Fieldwork was ethnographic with the researcher accompanying care workers in their visits to the care recipients' homes. Next to these 'trips', the researcher was also hanging around between activities at the community center and office where the home care team is based. Because of spending so much time in the habitat of care workers, it could have been the case that the researcher is more prone to take the perspective of the care workers, as she had broader access to their everyday working lives. The researcher took this potential bias into account during the analysis and presentation of data.

Access

Access to a fieldwork site was difficult and consequently delayed the work. The main reasons, as far as we could trace them are work-overload, privacy of care recipients and family members not willing to cooperate. We utilized two different strategies to acquire access. Firstly, a formal path was taken through directly contacting care organisations and organisations representing people with disabilities. Secondly, we utilized chain referral methods through our professional and personal networks.

Via web-search a list was composed of Dutch care providers, care intermediating organisations (temporary work agencies mediating between people with home care needs and home care workers) and patient organisations representing people with disabilities and/or elderly people. Following the list, five well-known and smaller care agencies have been approached. Two organisations declined to participate because of a heavy workload. The third organisation never replied nor answered our follow-ups. The fourth organisation expressed their interest, but at a certain point stopped answering our emails and follow-up calls. The fifth, a publicly well-known advocacy organisation representing the interests of people with disabilities did not have direct contact with people with disabilities and referred us to another organisation that they felt would be more suitable. That organisation never replied. Following this unsuccessful first round, various organisations have been approached, one team reacted positively and soon recruited a care recipient who consented to participation. However, his family members decided that he should not cooperate after which we had to start again. A final care organisation that had initially reacted positively then decided they could not participate, due to scheduling conflicts and heavy workload. This led to further delay in our planning. In the meantime, we were looking for another fieldwork location.

At the same time, a chain referral strategy was attempted by contacting colleagues, friends and relatives, asking them whether they were in contact with any care workers (organisations) or people who receive care at home. None of which was successful because either the care user was too ill or because an employer and clients refused consent.

In addition, through a colleague within the ETHOS consortium, we got in touch with two advocacy groups that focus on migrant communities in the Netherlands, who also refused to cooperate. Finally, respondents were found via a master's student of the department of Interdisciplinary Social Science. This student wrote her thesis on care work for which she has had contact with an autonomous home care team in Utrecht. That team was very interested in joining a care-oriented study. Immediately at the first contact they were happy to join in and to provide us access to our fieldwork sites; they very quickly contacted the care recipients who gave consent for the observations and interviews.

The mini-ethnography took place in a short duration of a week. The final interviews also took place in the period of this week, with one exception where the person was unavailable until the following week. Because the time-period of participation was limited, there was relatively limited time for participants to get to know the researcher better

and vice versa. Yet passing of time is crucial for participants to be willing to share their (private) views on and experiences with care work, to build a form of rapport. Still, when comparing the interview materials of the initial interview with the closing interview, the materials of the closing interviews show that the participants were more willing to express the in their eyes, more sensitive information. Thus, participant observation, even though it took place in a short period of a week, is of great added-value when compared to a stand-alone interview. Furthermore, the participant observation was also an added value, as it gave the researcher the opportunity to contrast practices with expressed views during the first interviews and inquire about real life examples of care practices during the final interviews.

The nature of the participant observation was that the researcher would accompany care workers in their visits to the care recipients' homes. Next to these 'trips', the researcher was also hanging around between activities at the community center and office where the home care team is based. Because of spending so much time in the habitat of care workers, it could have been the case that the researcher is more prone to take the perspective of the care workers, as she had broader access to their everyday working lives. The researcher took this potential bias into account during the analysis and presentation of data.

Ethics

Prior to the fieldwork, we attended a team meeting. The informed consent letter was handed over and the team members were informed about fieldwork procedures of our fieldwork on which she had several questions that could be answered. The actual fieldwork started with the distribution of the informed consent letter to all study participants and all other members of the home care work team. The team also received an email asking whether any of them opposed the presence of the researcher at the home care work agency. None of the care workers within the team opposed the research. However, not all of them would themselves participate in the research. Three care workers within the team that were involved in providing care for the selected care recipients agreed to participate in the study; to be interviewed and to allow us to participate in and observe their care activities. Before the initial interview took place, the researcher further explained the focus and aim of the study, her role in data gathering and asked all participants to sign the informed consent letter. The hard copies of the consent letters are kept in storage at Utrecht University according to the ethical protocol.

To assure the anonymity of the participants, all names and personal details of persons have been anonymized and only aliases have been used. Furthermore, specific information about personal details of participants have been changed where possible.

Sample

The research was conducted among three care workers and three clients (a couple and an older woman with limited mobility) of a neighbourhood home care team of nine different home care workers; all female. All are employees of a large national home care organisation that has won the municipal bid for this part of the city. Although they are employed by a large nationally operating care organisation, they operate autonomously in the neighbourhood.

For more details please see the national report available from https://www.ethos-europe.eu/sites/default/files/5.3_netherlands.pdf.

Methodology: Portugal

The methodology for this case study followed the guidelines designed by the work package coordinators. The first part comprised desk research and involved a review of academic literature and the analysis of policy documents, legislation and demographic data regarding the Portuguese population, types of care and profile of care workers. This first review allowed us to obtain the background information necessary to carry out the fieldwork, that is, the second part of this case study. The methodology chosen for the fieldwork was a combination of mini-ethnographies and semi-structured interviews. The ethnography is the basis for the fieldwork, as it was designed to observe, understand and explore the relationships between care workers and care users in private households. The semi-structured interviews were used to obtain more detail to add to the ethnographies, and particularly to add information that was not possible to obtain through the observations alone. In order to respect privacy, all names were changed and when someone was referred to by the participants and/or intervened their names were redacted.

The guidelines specific to the fieldwork were adapted because of difficulties with access.

Access

Unfortunately, the access was never easy: sometimes the relatives and parents of the care user were not willing to have someone 'strange' in their house; other times the care user did not agree to be observed in their intimate space. Therefore, in coordination with the coordinators of WP5, we agreed to adapt the field work: one field site was established through accompanying the mobile units of a Portuguese institution that visits dependent elders and provides home care. The goal was to compare this type of care with the care provided in a nursing home of the same institution. This solution was found through personal knowledge and contacts with the caregivers of the institution and we were confident that the relationships in this context would be interesting to observe and analyse. The mobile units would enable us to observe situations where families preferred to keep the elder at home, avoiding institutionalization for the longest time possible whether for emotional or financial reasons and we could also observe situations where although at home, elders were left alone. In the nursing home we had the opportunity to see how individuals tried to recreate the life they had at home and fulfil the idea they had in mind for their retirement age. In both situations, the care workers were very important, as they provide not only physical care but also emotional care to the dependents. All care workers were Portuguese females, as the institutions do not employ migrant workers (Wall & Nunes, 2010). Taking care of older people in Portugal is mostly carried out by Portuguese women, and it is still very rare for men to work as caregivers partly for cultural reasons – women are perceived as the responsible for care provision – but also because most of the care users are women and they do not feel comfortable with men providing them with physical care.

Ethics

Prior to the beginning of the observations and interviews, following the guidelines of ETHOS project, the letter and consent form was sent to CES ethical commission as well as the guidelines for us to obtain ethical clearance. After the formal authorization from the commission, the same documents were presented to the administration of the institution in which the fieldwork was done for them to also approve. Also, as demanded, for each individual participant the research study was explained and their oral and written consent was collected.

It is important to mention some limitations and discomfort felt with the fieldwork. We consider one week to be too short to observe the reality of the relationship between the caregivers and care users. Although we had

authorization to perform the observation in the institutions, during the fieldwork we had to adapt to the schedules of the caregivers and their own will to participate in the research. The two first days of the fieldwork served to establish a relationship of trust between the researcher and the participant, which was not easy. Most of the caregivers felt observed and judged, despite the constant reassurance by us that they were not being evaluated on their work and that they should perform as they are used to do in their everyday working life. It became difficult to go unnoticed. One way to avoid this was to choose not to take notes during the observation, since it was clear that seeing someone writing was altering the behaviour and attitude of the participants. Care workers' lack of time and availability somehow compromised the development of the interviews, which were too short to really understand the key issues they felt regarding their profession. Regarding care users and their families, orally and written consent was given and no one refused the presence of someone who were not from the mobile unit's teams, since they assumed that the new presence to be a trainee/making an internship. However, they asked questions about the new arrival, in particular for how long the presence in the institution would last. In some cases, it was difficult to explain that the goal was to carry out a research.

Sample

Because of the access difficulties outlined above fieldwork was conducted in two sites. The first was through accompanying mobile units, where the sample consists of two experienced female mobile care workers, one male care receiver and his daughter. The care receiver is an old man with mobility limitations who lives alone and get three time a day support from the mobile care workers. In addition, a male administrator of the mobile care units has been interviewed.

The second site was a care home run by the same institution. There the sample consists of two care workers, one woman returning from emigration to Switzerland, the other a young woman who entered the job after finishing secondary school. Two care receivers form a couple who moved in the nursing home together because of some mobility problems. Another interview was conducted with a daughter of a male care receiver who moved into the nursing home because he lost all his mobility after a cardiovascular incident.

For more details please see the national case study available from https://www.ethos-europe.eu/sites/default/files/5.3_portugal.pdf.

Methodology: Turkey

Using national data and academic and policy literature on care work an overview of migration and eldercare in private households in Turkey was compiled and shared with the WP coordinators.

Access

The field study was conducted from May 2018 till July 2018 and participants were accessed using personal contacts. There were certain methodological difficulties in the ethnography study regarding access to households. Given that the study was going to be finished in 5-6 weeks, building trust with the families to conduct such work of ethnography that intervenes in the intimate lives was a major challenge. It was not easy to persuade care receivers and their families to conduct an ethnographic study that would last for a week where the researcher had to spend time in their homes. Elderly people and/or their families were understandably reluctant to have a 'stranger' in their house. Moreover, most of the care receivers we have worked with have mental disabilities and so could not be

included for ethical reasons. Furthermore, the field study coincided with Ramadan which also affected participation. The time limitations imposed by the study made access even more challenging.

Once access was granted it was necessary to build trust with the families in order to conduct ethnographic work. Being polite, cheerful and giving accurate information about the study facilitated the establishment of the trust relationship between the researcher and participants. Almost all participants felt more comfortable after the end of the first day of ethnographic study and the trust relationship between the researcher and participants was established earlier than expected. The researcher generally left the field (house) around 6 pm. Hence, all the participants invited her to have dinner together. The researcher was invited to the lunch table and they had their meals together during the day indeed. The researcher spent one week with each family but did not attend when the care givers were off work and out of the house. In some cases, care receivers did not want to participate in the study with visitors present. Apart from those interruptions in the house, the guidelines to spend a week in the house was completed over the course of the project. We should note that the design of the ethnographic study was questioned by our Ethics Committee as building trust in that short period of time was the major challenge which was also revealed by our experience as researchers.

All participants were accessed via personal contacts in Istanbul because of time constraints but factors such as ill health and bereavement meant that our initial contacts did not bear fruit. This might be related to the fact that Istanbul is a huge city with a dense population and comparatively difficult living conditions making people's daily lives more isolated and more distrustful of 'strangers'. Ethnographic work that demands access to the intimate lives is already contested issue which pushes one to critically explore not just the class and cultural aspects but also spatial aspects with regard to where the research is conducted.

Then it was decided to switch to Ankara because this is the city where the project researcher was born, and her family still lives there. Via personal contacts persons were reached whose mothers or fathers are cared for migrant care workers. Then, the researcher called the family, shared information about the ethnographic study and asked for their permission to be contacted. Here, being polite and sincere and explaining the project requirements clearly and openly were very important to persuade people to participate in the study. The care users and care workers who accepted to participate in the study and signed the informed consent form were included as research participants.

We used different routes to follow up depending on whether our initial contact was with the care receivers or care workers. Permission to access houses through the care worker was much more difficult than access through the care receiver for obvious reasons. Many care providers we contacted in the first place did not agree to be observed in their workplace since many work without valid work and residence permits. Since we were strangers coming from a public institution, some workers did not want to participate in the study. We should note that majority of care workers who participated in our study had a work permit. When we had access to the house through the care receiver permission was much easier and this in turn affected care workers' willingness to participate in the study. As in our earlier efforts in Istanbul there were cases where the care receiver agreed to participate but had to pull out because of health problems but we managed to reach the target number of cases.

In addition to the mini-ethnographies we also conducted interviews. We used the questions provided in the guidelines as guidance only, adapting them to the Turkish context. In coordination with the coordinator of WP5, we agreed to make amendments in the questions that would work better in the Turkish context. For instance, the last

question of interviews concerning a vignette scenario was revised. In the scenario, we changed the wording ‘racist’ to ‘insulting’. We also changed the phrase ‘the stealing the money’ to ‘breaking a vase’ that refers to a possible conflicting situation as stealing money could have been perceived by the care provider as an interrogation. Furthermore, some questions had not been comprehended completely as the participants were not familiar with certain concepts in the interview questions. Before starting to conduct field study, we were not sure about the question of unionization since unionization of the migrant workers was not a reality in the Turkish context; they usually do not know anything about unionization of care workers. Nonetheless, we kept this question during the interviews of the first and the second cases. After receiving the reaction of the first participants (they did not understand the question and they could not give any meaning to it), the question on unionization was removed as it did not work in the Turkish context.

The interviews were recorded (with the written consent of the research participants) and field notes of the ethnographic study were taken throughout the research. The recorded data was transcribed and anonymized through the usage of pseudonymous names. The analysis was carried out in Nvivo qualitative analysis software; following the analysis, the quotes, the passages and other ethnographic data used in the report were translated to English from Turkish. An informed consent form for the interviews and permission for accessing the houses were prepared. The researcher thoroughly read the consent form to the participants explaining the purpose of the study and their right to withdraw at any time. Care providers and care receivers were also informed that their interviews would be anonymized.

Ethics

The study was approved by the Ethics Committee of Boğaziçi University. A comprehensive ethical application form that includes the ethical considerations of the research and measures was taken to conduct ethical research by the project team was filled and applied to the Ethics Committee. We should note that Bogaziçi University Ethics Committee follows strictly universal rules for the ethical research and Committee demands the applicant researchers to provide accurate and detailed information about all stages of the research to be conducted. To receive the Committee’s approval, we were very careful with our research design that also complies with the guidelines of the WP5. In summary, full name of the project, brief summary and methods of the project, the names of the project team (project managers and researcher) and their contact information were provided in the ethical application form. Besides, ETHOS Case study protocol-D5.3 and a sample of consent form were also shared with the Committee to ensure clear information about the research. On 2 May 2018, we have received our ethical approval. After the ethical approval was provided to us, we had start field study. No major ethical dilemmas were faced in the fieldwork as the ethical issues were considered beforehand and care receivers with mental disability were not included in the sample. The researcher took all the measures not to give any disturbance to the daily life of the families who kindly agreed to participate in the research. During the interviews, the voice recorder was used with the permission of the participants. All participants accepted the recording. Quotations of participants were provided at the final report with pseudonym names.

Sample

Despite the access difficulties outlined above the sample consists five care workers and six care users. All care workers are female migrant care workers living in the houses of the care receivers. All care receivers are above 80

years old, and among them are two couples, of one couple only the man could be interviewed because of the mental disorders of his wife. Two other care receivers are women and one is a man, all are widowed.

For more details please see the national case study available from https://ethos-europe.eu/sites/default/files/5.3_turkey.pdf

Appendix Three: Training for Researchers for D5.3 national case studies

WP5: 'Mapping of everyday negotiations of conflicting claims for justice with attention to the role of gender and ethnicity'

Preparatory work

The training session in Coimbra next month will be an introduction (or refresher, depending on your background and previous experience) to ethnographic fieldwork. We will focus on the specific value and challenges of short-term or mini-ethnographies, and on doing research in private homes. Please make sure you read the study protocol and the following articles before the session (PDFs attached):

Ferguson, Harry. 2018. "Making home visits: Creativity and the embodied practices of home visiting in social work and child protection." *Qualitative Social Work* 17 (1):65-80. doi: 10.1177/1473325016656751.

Madden, Raymond. 2017. *Being Ethnographic : a guide to the theory and practice of ethnography*. Los Angeles: SAGE. ['Chapter 1: "Definitions", methods and applications'].

Pink, Sarah, and Jennie Morgan. 2013. "Short-Term Ethnography: Intense Routes to Knowing." *Symbolic Interaction* 36 (3):351-61.

Some questions to consider:

- In light of Ferguson's article, consider the degree to which the social worker expression 'working the house' might be applicable to both care-workers and the ethnographer (i.e. you): what instances and practices of 'working the house' do you expect to encounter during your fieldwork and what dilemmas and challenges do you expect to arise from them? □
- How do you expect to 'work the house' during fieldwork? (think about spaces and interactions, how to relate to care-workers, care-receivers, and other people living in the homes). Will you be able to and comfortable moving around the house (including kitchen, bedrooms, bathrooms, hallways, living rooms, etc.) with your research subjects, and what might be gained from interactions and interviews conducted in different spaces? □
- In light of Pink & Morgan's argument for the value of short-term ethnography, how will you seek to ensure that your fieldwork is 'data-intensive'? (visual images, videos, recordings, note-taking, embodied practices of care, etc.?) □
- Think about atmosphere, and sensory and embodied impressions of homes, and the role of objects; how will you aim to capture these for analysis later? How will you seek to access the experiences of atmosphere of care-workers and care-receivers respectively?

Training days

Thursday 13.45-15.45

13.45-14.00 **Introductions** (name, role, prior experience of and training in ethnographic methods)

14.00-14.30 **What is ethnography?**

- Being with *and* writing about people; encompassing both doing *and* writing up research
- Endeavours to understand emic perspective; ethnographer moving between emic and etic perspectives
- An embodied process involving creativity, craft, and improvisation; importance of ‘being there’; establishing empathy and using resonance
- Interest in claims *and* acts / discourse *and* practice, *and* the gaps and discrepancies between them
- Rich, granular data (good for capturing complex relationships and emphasises importance of embodied and tacit knowledge / practice)
- A learning process (role of faux pas, cultural translation between potentially incommensurable worlds)
- Interdisciplinary and enduring, yet changing, social science method

Short-term or mini-ethnographies:

- Punctual & focused vs. holistic & open-ended (intensive excursions)
- Interventional and observational (close and intentional focus on details of everyday practices; interventions to make the invisible and unspoken emerge)
- Data-intensive (reflect on different data collection methods, what constitutes data, how to ensure richness – for further discussion on Friday)
- Role of theory
- Interest in practice and practical activities (here: care work and care receiving)
- Inductive *and* deductive

14.30-15.15 **Ethnography in/of the home**

- ‘Working the house’ (Ferguson); different spaces; what happens where and when; permitted and closed-off spaces for researchers and research participants (e.g. live-in care givers)
- Atmosphere, reverberations, objects and material culture (‘things do things to us’; the feel of places, smells, sounds, touch)
- Asking research participants to perform and explain everyday tasks (researchers to participate)
- Dealing with awkward situations and drawing boundaries (think about toilet and bath visits, intimate care situations, bedrooms, arguments between research participants)

Ethnography as embedded and embodied

- Using the ethnographer's body as tool: the importance of capturing the non-representational and the taken-for-granted; the challenge of articulating and translating unspoken, tacit knowledge, hidden experiences, senses, emotions, movements, embodied practice
- Inter-subjectivity
- Role of empathy and resonance
- Body techniques and habitus: thinking of care work and care receiving as learning processes (the challenge of and need to articulate everyday minutiae and detailed bodily practices); consider asking participants to perform everyday tasks for recording and discussion. Where appropriate, ethnographer to emulate (need to think carefully about situations/practices that are/are not appropriate and ethical)
- Asking intrusive / 'irrelevant' questions (can be awkward, but also revealing and open up for reflection and discussion)

15.15-15.45 Validity and comparability of data; access consent and ethics

- Validity, veracity, reliability (how to deal with incommensurable accounts)
- Systematic data gathering (how to ensure data intensity: photos, filming, audio recording, drawings/sketches, maps of rooms and the home)
- Systematic data interrogation (strategy for analysis)
- Presentation of the ethnographic story Agree a template for field notes with prompts? (e.g. timing activities, noting mobility in the house, 'atmosphere', who is present, etc. Note Ferguson's descriptions – how can you ensure same level of detail)

Friday – 45 minutes

Access, consent and ethics

- Presentation of self and research project – info sheet and consent form
- Obtaining meaningful consent from all involved parties
- Dealing with withdrawal of consent (this covered in our ethics procedures)
- Dealing with disclosure of abuse [need procedure and clear guidelines that are locally relevant and links with local services] this will have to be covered in the consent procedures. I will flag.
- Interview schedule / guide
- Agree on platforms and frequency for staying in touch during fieldwork and sharing of notes
- Language issues? – E.g. where care giver and care receiver have limited shared language; will care givers be interviewed in their first language? Use of interpreters?

Appendix Four: Suggested interview schedules

1. Initial interviews with care users/employers/family members

1. History of care needs and how these were met until now (including family members' history of caring for their relative)
2. What do they think of current law and policy with regard to care – do they feel that it is just? If not, why not? What are its benefits and how could it be improved.
3. Thinking about your current situation, what would make it more just or more fair?
4. In what way does employment of someone in your house/having someone into the home differ from employing someone in a business? (i.e. how important is the *site* for relations).
5. In what way does paying for care differ from paying for other services like cleaning? (i.e. how important is the *nature of the work* for relations).
6. What are the best and worst aspects of your day?
7. What would be the characteristics of a good employer?
8. What would be the characteristics of a good care giver? Is it the same if they are paid or unpaid?
9. What skills are needed for care work?
10. In general do you think care workers are treated with respect in this society?
11. Do you think that paid caregivers should have the same rights as standard workers?
12. Some people say they treat caregivers as part of the family rather than workers. What do you think of this?
13. What do you think about unionisation for care givers? If think it is not a good thing, why?
14. Can you give me an example of where you had a disagreement with your current or a past care giver and how you worked it out? What lessons did you learn from this?
15. Consider this scenario:

Anna is a migrant worker who has been working as a care worker for Tom in his house for four weeks. Tom is becoming forgetful and his daughter, Maria, employs Anna to be in the house from 9-5 while she is at work. One day she comes home to find Tom very distraught. Tom says that he had set aside some money for shopping and that it has disappeared. Anna says that she has not stolen the money. She also says that Tom has been using racist words in his dealings with her.

What should Maria do?

What should Anna do?

Would it be different if Anna had worked longer for the family?

Care homes

16. What do you most like about this place, and what do you dislike (trying to get at whether they feel at home)
17. Do you think the people who work here are paid well? Do you think they enjoy their work (probe on hours and conditions)

2. Initial interviews with commodified care workers

1. How long they have been working in the sector/being paid for their work. What they think of this arrangement.
2. In their own words, how would they describe their relationship with the person/people they care for? Has it changed over time?
3. What do they think of current law and policy with regard to care – do they feel that it is just? If not, why not? What are its benefits and how could it be improved.
4. In what way does working in a private house differ from working in a business? (i.e. how important is the *site* for relations).
5. In what way does being paid for care differ from being paid for other services like cleaning? (i.e. how important is the *nature of the work* for relations).
6. What are the best and worst aspects of your day?
7. What would be the characteristics of a good employer?
8. What would be the characteristics of a good care giver? Do you think that a good paid care giver gives the same kind of care as an unpaid family member?
9. What skills are needed for care work?
10. In general do you think that care workers are treated with respect in this society?
11. Do you think that paid caregivers should have the same rights as standard workers?
12. Some people say they treat caregivers as part of the family rather than workers. What do you think of this?
13. What do you think about unionisation for care givers? If think it is not a good thing, why?
14. Can you give me an example of where you had a disagreement with your current or a past employer/care user and how you worked it out? What lessons did you learn from this?
15. Would you prefer to work in people's private homes or in an institutional setting? Why?
16. Consider this scenario:

Anna is a migrant worker who has been working as a care worker for Tom in his house for four weeks. Tom is becoming forgetful and his daughter, Maria, employs Anna to be in the house from 9-5 while she is at work. One day she comes home to find Tom very distraught. Tom says that he had set aside some money for shopping and that it has disappeared. Anna says that she has not stolen the money. She also says that Tom has been using racist words in his dealings with her.

What should Maria do?

What should Anna do?

Would it be different if Anna had worked longer for the family?