



Left out in the cold: Informal home care in Hungary

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This Working Paper was written within the framework of Work Package 5 (justice as lived experience) for Deliverable 5.3 (comparative report on competing claims for justice and everyday practices of recognition and redistribution in commodified care relationships in the private households)

February 2019



Funded by the Horizon 2020
Framework Programme of the European Union

Acknowledgements

The author would like to thank all the individuals who participated in this research. While only a fraction of their rich experiences and views is reflected here, the author hopes they will find it faithful enough to their own experience. The author would like to express her gratitude to the many insightful comments, observations and questions received from Bridget Anderson, which may not have found their proper response with this report yet and many thanks to the help and support showed by Pier-Luc Dupont during the entire reviewing process. All errors and mistakes are the author's.



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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.

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

About ETHOS

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

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

ETHOS does not only understand justice as an abstract moral ideal that is universal and worth striving for but also as a re-enacted and re-constructed 'lived' experience. This experience is embedded in legal, political, moral, social, economic and cultural institutions that claim to be geared toward giving members of society their due.

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

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

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

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

Utrecht University in the Netherlands coordinates the project, and works together with five other research institutions. These are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019.

EXECUTIVE SUMMARY

This working paper focuses on justice as 'lived experience' through attention to commodified care relationships in private households. Focusing on care relationships based on informal care in Hungary, the study analyses the experiences of (in)justice and accommodation of justice claims in the lives of adult physically disabled and frail elderly care users, care workers and close relatives participating in commodified care relationships in private households. It looks at how the participants in the care relationships understand and manage competing claims for justice in everyday practices of recognition and redistribution and how daily conflicts of justice claims are understood and managed (or not). As studies (EUROFAMCARE 2004, Széman 2004) have concluded in Hungary the family is the most important care provider. Due to quality and quantity related problems in the formal care market and the high costs in the visible care market families typically resort to a special invisible care market to employ undocumented (non)-Hungarian carers. The report asks what kind of life care users/care givers want, i.e. what gives them pleasure or contentment in their everyday lives, what helps them achieve this, and what obstacles they encounter. The report explores how demands for justice/fairness as recognition, representation and/or redistribution were made and to whom these were addressed. It aims to reveal the words and frames used in what might be called as justice claims and how conflicting justice claims are negotiated. Last but not least, it interrogates the role of the state in such commodified care relationships with respect to justice.

This study is based on 'mini-ethnographies', in this case comprising daily home-visits 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 care relationships, was central in bringing them about. The mini-ethnographies and the semi-structured interviews took place between May and July 2018. 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.

Both the care givers and care users lived and experienced justice and injustice in the context of an understanding that home care meant a special kind of work, where emotional investment, attachment, and trust played a defining role. Within the private households observed the daily acts of recognition could happen in the spirit of fairness and reciprocity, tolerance and sensibility. Injustice was also experienced in light of the attachments and bonds formed when these bonds were broken. For justice to work, the experience of care encompassing both the care givers, the care users and the close relatives, that is, an entire network of care, should be part of the knowledge that the state has and on which it is willing then to act upon. A step forward would be in general for the Hungarian state to recognise the importance and omnipresence of care in society. As a more immediate step it could recognise the existence of informal care and incorporate it and regulate it, and with respect to the care allowance not only to increase the total payment but to recognise home care as work.

CONTENTS

EXECUTIVE SUMMARY.....	4
ACRONYMS.....	6
1. INTRODUCTION	7
2. NATIONAL CONTEXT.....	8
2.1. Situating home care in Hungary based on the national literature review	8
2.2. Legal framework.....	13
2.3. Relevant available national data	15
3. ETHNOGRAPHY.....	19
3.1. Care maps	19
3.2. Mobility and autonomy	21
3.3. Access	22
3.4. The house on the hill: Where emotional bonds end. First care relationship.....	24
3.5. Working mother: Second care relationship.....	28
4. CONCLUSION	32
BIBLIOGRAPHY.....	35

ACRONYMS

HCSO Hungarian Central Statistical office (in Hungarian KSH)

HCSOM Hungarian Charity Service Association of the Order of Malta

HCLU Hungarian Civil Liberties Union (in Hungarian TASZ)

1. INTRODUCTION

This working paper focuses on competing claims of justice in commodified care relationships in private households, including care users, care givers and close relatives. More specifically it looks at the experiences of (in)justice and accommodation of justice claims in the lives of adult physically disabled and frail elderly care users, care workers and close relatives.

In the summer of 2018 a grassroots mobilisation and movement led by advocacy groups such as *Lépjünk, hogy Léphessenek Közhasznú Egyesület*, ('Let's step so that they can step as well'), *Csak Együtt van Esély (CSEVE) Csoport* ('Only together do we stand a chance'), and *aHang* ('The Voice') and supported by extensive coverage by opposition online media brought home care, and more specifically the home care of disabled persons to the attention of the general public raising awareness of the plight of those caring for disabled family members and required to live on only the care allowance provided by the state. The long-term goal was to have the care of disabled family members legally recognised as work. Assessing the trend in long-term care in Hungary Szémán (2015) argues that in the context of increasing demand for care between 1993 and 2008, families have been forced to take upon themselves the care of their elderly family members and at the same time the state support for this have been eroded and systematically dismantled. The Fundamental Law (Constitution) of 2011 which enjoins families to look after their frail elderly has not been backed up by measures or policies that would make this possible, with the state increasingly relinquishing its obligations in this field.

Given the prevalence of families employing undocumented carers when it comes to home care in Hungary, the report is based on the analysis of such informal care relationships as revealed through a set of mini-ethnographies. The field is constituted primarily through daily home-visits which lasted approximately five-hours conducted over a period of between one week and ten days. The mini-ethnographies were complemented by semi-structured interviews with all the participants involved in these commodified care relationships and later with shorter follow-up questions regarding the current state of the care relationship. Two semi-structured interviews were also conducted with a mediating person, who while not directly involved, was central in facilitating one of these care relationships. The mini-ethnographies and the semi-structured interviews took place between May and July 2018. The length of the interviews lasted between 20 minutes and one and half hours. 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. All participants were anonymized and to further protect their privacy, the names of specific institutions and organisations were removed from direct quotes. Interview transcripts and ethnographic notes were uploaded to a secure server and all analysis was conducted directly by ETHOS project members.

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. As a researcher I was highly dependent on these networks and my choices of families were constrained by these. My gatekeepers, having been introduced to the aim and scope of the research, directed me to families that they thought were the most helpful ones for this purpose. Often initial leads came to a dead end, or ethical concerns compelled me to opt for a different household. Thus, these ethnographies are in no way representative of a larger population. A much more extended

fieldwork, encompassing more households and lasting for a considerably longer period of time would have taken the research much further.

My institutional affiliation to the Central European University and the fact that this research was part of a larger EU research project were significant factors conditioning my access. In the heated political climate of Spring 2018 with the Hungarian national elections approaching, the CEU and the European Union were polarising institutions meaning that some respondents declined to take part in this study while others found it important to support it. During the mini-ethnographies I tried not to cause tensions in this respect. 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.

In order to contextualise the analysis the report first maps the larger Hungarian background through a brief literature review of works relevant to commodified home care, the presentation of the relevant legal framework and a selection of available national data. It is followed by an ethnographic section based on mini-ethnographies conducted in private households. The conclusion synthesises the findings with a view to informing deliberative democratic theories and concepts in the light of commodified care relationships in private households.

2. NATIONAL CONTEXT

2.1. SITUATING HOME CARE IN HUNGARY BASED ON THE NATIONAL LITERATURE REVIEW

Hungary is an ageing society. The population over 60 will be almost double that under 20 by 2050: more than one third of the population will be over 60 years and by then the two baby boom generations (1950s and 1970s) will belong in this age group (KSH/ Central Statistical Office 2003). The proportion of persons aged 65 years and over has been rising sharply from 15.1% in 2001 to 16.2% in 2008 and it is estimated that by 2050 those aged 65 and over will make up 29.4% of the population, while the proportion of those aged 0–19 years will fall to 18.4 % by 2050 (HCSO 2008; KSH 2005). This is in part a good news story: by 2060 the average life expectancy at birth is projected to rise to 81.9 years for men and 87.3 years for women (Eurostat 2008). But while life expectancy at birth is increasing, healthy life expectancy is not. The WHO figures on average healthy life expectancy at birth show a very negative picture for Hungary compared to other countries: only 62 years for men and 68 years for women (WHO 2006). Out of 29 countries (EU plus Norway and Switzerland) Hungary was ranked 25th. In the majority of Eastern European EU member states healthy life expectancy was between one and five years higher.

The proportion of the population over 65 years of age increased substantially in Hungary to 13.1% in 2013¹ and that of the 80+ age group grew from 2.9% in 2001 to 4.1% in 2013.² In 2012 life

¹ This is the same as the average of the EU28.

² 'Népesség korcsoportonként (2003–2014)', Eurostat data table, retrieved 28 Apr 2015 from the website of the Hungarian Central Statistical Office, www.ksh.hu/docs/hun/eurostat_tablak/tabl/tps00010.html.

expectancy for men over 65 was 14.3 years, and for women 18.1 years, but the healthy life years (HLY) expectancy fell far below that level to only 6.4 years for both men and women. According to the most recent census (2011), 40% of those over 60 (more than 900,000 persons) have a chronic illness; more than one in ten of them cannot live independently, one third in their everyday life and more than one quarter find it difficult to use public transport. A further 11% of those over 60 live with some form of disability (physical disability, impaired sight, impaired hearing) (KSH 2014). On the other hand, long-term care expenditure as a share of the GDP is very low at less than 0.5%. Among all OECD countries, lower levels are found only in Estonia, Portugal and Greece. The contrast with the Netherlands and Sweden, both states which have recognised the challenge of long-term care and developed appropriate policies (OECD 2013), is especially striking (3.8% and 3.6%, respectively), in 2011 (Széman, 2015).

Thus Hungary's demographic situation suggests considerable and growing care needs. According to Ferge's (2017) and Széman's (2015) assessments of the trend in long-term home care in Hungary the Social Welfare Act of 1993 (1993. évi III. törvény/act) was an important step in the history of the welfare state and foundational to social assistance in post-1989 Hungary. With respect to the present focus of this research, the Act made it mandatory for local authorities to provide home care (for a maximum of four hours a day) and meals for persons over 60 in a normative-based financing system. Towns with over 2,000 inhabitants were required to operate a so-called 'seniors' club', providing meals, activities and personal hygiene, both as a specialised service, and as a service that NGOs, churches and the private sector could provide. The standards of the 1994 regulation (e.g. sqm/person in residential homes, 2/1994. (I. 30.) NM rendelet/decree, 9/1999. (XI. 24.) SzCsM rendelet/decree) meant further qualitative improvement. However, small towns and disadvantaged regions were unable to meet the requirements to provide basic services. An examination by the State Audit Office in 2004–2005 revealed that post-payment financing³ was the reason why home care coverage stood at only 66.6% (State Audit Office 2007). In 2009, 75% of towns with fewer than 400 inhabitants were able to provide home care, and 70% meals (KSH 2011, 1–3). In 2006 the model of home care with emergency alarm developed by HCSOM (Hungarian Charity Service Association of the Order of Malta) in 1992–1994 was incorporated into the Social Welfare Act. The organisation became a Centre of Methodology with the right to monitor and train. However, a negative trend began in 2008 (36/2007. (XII. 22.) SZMM rendelet/decree, 340/2007. (XII. 15.) Kormányrendelet/governmental decree) which brought repeated budget cuts together with the withdrawal of the methodological authorisation from HCSOM, with only towns with more than 3,000 inhabitants required to operate a seniors' club. That meant the elimination of 8% of towns from this provision (State Audit Office 2007).

In the case of residential homes the threshold for mandatory provision was raised from 10,000 to 30,000 inhabitants and the conditions for admission to a residential home were also modified with only persons requiring over four hours of care a day accepted. This according to Széman (2015) shifted care towards nursing without providing the necessary health services or strengthening home care. Home nursing that could be provided for two weeks (financed by the Health Fund) solved only the

³ In 2004, 3% of all persons over 60 received home care; 5% meals on wheels; 2% attended clubs for the elderly; home nursing was provided for 0.4% (PaPházi 2005).

problem of acute need for health care and did not constitute a supplement to long-term home care in the social sphere.

By 2012 the formal care system was struggling with serious problems of quantity and quality. The number of persons receiving home care trebled between 2000 and 2012 (from 40,212 to 125,281), but this was not followed by a similar increase in the number of care workers. The net result was a significant increase in the number of people care workers were responsible for: from 4.3 elderly persons per carer in 2000 to 7.3 by 2011 (Hungarian Central Statistical Office/KSH 2012, Table 7.3).

Home care in Hungary while widespread is by far less common than institutional care both for people with disabilities and for the (frail) elderly (Szabó 2013, 2014). Szabó (2014) noted the tendency among families to resort to institutional home care of the frail. Elderly care in Hungary builds on long-term residential care and, despite attempts to move towards home care, most elderly care still is given via large institutions or as residential care away from the home of the frail elderly (Szabó 2014). There is no geriatric counselling available to families to help them decide what sort of elderly care to use. Service provision is based on a restrictive and simplistic assessment of care needs which follows an institutional logic. When it comes to individual cases one rarely sees complex care assessments including a consultation with family members, or work towards helping families find the resources and supportive background. The legislative background is also unsatisfactory (Szabó 2014) resulting in the restricted room for manoeuvre of basic social care provision. In 2014, twenty years after the social law/Social Welfare Act was passed it was still not clear who is reached by existing care arrangements, and whom they should reach (Szabó 2014). In addition, current practice tends to take a medical approach, with hospital care as a model. Big, centralised institutions are dominant even though such institutional care has largely proven to be inadequate for a person-centred approach. Often long-term homeless people are directed towards institutions for elderly, and disabled people are also sent to elderly care homes.

At the same time the elder care is more and more a matter of social provision and less a service within the health care system, the latter unburdened in this respect, but resulting in more strain placed on the social sector. This means, for example, that there are very few medical doctors in homes for the elderly, with GPs, who are not necessarily prepared for this, left to deal with the elderly. In the past, institutional lead nurses with college or management degrees used to play a key role in elder care provision. They have been lately replaced by social carers who are regarded as better prepared for home care. (Szabó 2014) As a profession, elderly care has little or no professional status, and fewer and fewer resources. There are no incentives for those who work in home care to acquire a higher level of education and the general attitude is that home care does not need much expertise.

While the longer trend in elderly care is towards the strengthening of home care, aiming to keep the frail elderly or disabled person as long as possible in their familiar home environment this lacks momentum and happens in a very haphazard manner. In practice provision is for a very limited number of hours per day if delivered through the local council, and for a longer period it is usually through the largely invisible and unregulated informal care market.

The assessment of need and the ensuing basic/core/primary care provision provided by formal home care in Hungary, results in a very basic care provision which follows an institution-centred approach, which is by now considered to be a rather obsolete 'care management' form (Szabó 2013).

Care is restricted to physical support (shopping, cleaning) with strict time limits, and no provision for broader, psychological care. It is rare to see a more complex attitude to home care of the elderly. Szabó (2013) concludes there is a need for a more complex and nuanced care assessment than the overly narrow scaling system currently in use (Szabó 2003, 2010). He argues for a more holistic approach, emphasising the importance of support networks (Biegel et. al. 1984; Cress 2012; Lubben 2006 in Szabó 2010). In the long term this would require state recognition of informal care in order to incorporate and regulate it a manner that allows the network to really function giving all parties the recognition they deserve. It is probably a truism by now, that informal care rests on personal commitment, motivation and long term emotional support. When provided by family members it comes with considerable emotional strain and potential for conflict. Informal care is usually delivered through a network of family members, friends and others in close contact with the care user and can be in an antagonistic relationship with more professionalised care with formal care disassociating itself from informal care. On the part of formal carers there is little inclination to mobilise community resources, to tap into the already existing supportive network of informal family and community support while there is no easy fit between formal health and social services. Informal and formal care rarely meet and it is difficult to see how they can work together. Szabó (2014) cites foreign models, such as the 'hierarchical compensatory model' (Cantor, 1979) or Litwak's 'task specific model' (1985) on the cooperation between informal and formal/professional carers, notwithstanding a tendency on the part of professional carers to underestimate the role and contribution of informal care.

As noted above, elderly care is not really seen as a professional matter and Szabó (2014) notes the need for a professional qualification in elderly care and the urgent need to strengthen education and training level in this field. Currently there are few qualified staff, social workers or nurses with a degree working in elderly care, and of these many are forced into administrative and organisational roles (Szabó, 2003). In practice it is difficult to distinguish between care activities and more generally helping the elderly. As Szabó explains (2013, 2014) elderly care as a separate profession is not sufficiently differentiated from more general care activities, and there is no clear career trajectory/path for those who work in elderly or geriatric care. There is also a lack of modernised/ up-to-date care provider institutions.

In addition to all these difficulties, the regulatory system contains a paradox: In principle the operation of service provision and the assessment of need is delegated to the local level but there is a strong tendency to draw this field under centralised control. (Mózer 2014) Due to inadequate and weak state regulation the bulk of the Hungarian social services appears as a private service and this seriously limits access to social services. The Hungarian eldercare system is struggling to cope with numerous gaps and one of the most serious is the lack of provision for long-term care. Shortages in the care system and the inadequacy of solely family-based solutions together with the social and economic constraints of home communities lead to the formation of an invisible care market well known to society but not acknowledged by decision makers. Qualitative research conducted between 2009 and 2011 examined this 'invisible' aspect of long-term care provision (Szémán 2014).

One of the foci of this study were families employing undocumented migrants including ethnic Hungarians from neighbouring Romania (Transylvania) and Ukraine (Subcarpathia). Based on analysis of macro data and empirical research, the paper identified several care strategies utilised by families caring for older people in Hungary: 1. active family carer; 2. inactive family carer; 3. family carer receiving a care allowance; 4. family care with shared responsibility; 5. family employing legal carer;

6. family employing undocumented non-migrant carer; 7. family carer with earnings in the informal economy; and 8. family employing undocumented migrant carer. Széman cites the EUROFAMCARE⁴ (2005) project which produced a European review of the situation of family carers of older people in relation to the existence, familiarity, availability, use and acceptability of supporting services; the use and non-use of those services and the reasons behind them; effectiveness and efficiency; claimed needs for support resulting from the individual family care situation; and the specific types of family care situations and their relation to specific services or the lack of service. In addition to the six core countries (Germany, Greece, Italy, Poland, Sweden and the United Kingdom). This project included a pan-European review with national reports on 17 other countries including Hungary (Széman 2004), providing background information about the support, relief and expertise of family carers in the context of different social, health and welfare systems. One of its findings was that in Hungary the family was the most important care provider.

Széman (2012) remarks that there is no research data on undocumented migrant people working in care while the employment of invisible migrants is a part of long-term strategies of family care. The high costs of long-term care in the visible market care sector compels families to rely on undocumented carers, either from local Hungarians or migrant elder carers. In the nineties the cost of long-term care in the private care sector given by undocumented local Hungarians was also too high, families turned to the other cheaper solution and employed undocumented migrants living in. The invisible presence of ethnic Hungarian migrants coming from neighbouring Romania and Ukraine has been playing an important part in Hungarian eldercare. By employing them the upper and middle classes or those with savings have been able to ease the burden of long-term care and avoid institutional care⁵. There has been changes to this pattern as of late, with Transylvanian (Romanian) workers less willing to take up work in Hungary, with more and more Ukrainian people and Hungarians from the less prosperous parts of the country taking this role.

The process of de-institutionalization has received recent attention from NGOs. These include the Hungarian Civil Liberties Union (TASZ), which seriously criticised how de-institutionalisation was being implemented by the government⁶. They found that accommodation was being built in small, isolated villages, far from services despite pledges to integrate people with disabilities. Moreover, many of those who lived with their families hardly received any service, and often lived in even more difficult conditions. More Central and East European countries made use of the Structural Funds of the EU to build new or modernize existing large institutions. This according to TASZ posed serious problems for the EU itself as the EU ratified the UN convention on the right of people with disabilities which prohibits the maintaining and building of new large institutions.

⁴ See <https://www.ukc.de/extern/eurofamcare>. EUROFAMCARE is an international research project funded within the 5th Framework Programme of the European Community, Key Action 6: The Ageing Population and Disabilities, 6.5: Health and Social Care Services to older People, Contract No QLK6-CT-2002-02647 EUROFAMCARE. It does not necessarily reflect the Commission's view and in no way anticipates its future policy in this area.

⁵ See http://real.mtak.hu/37009/1/hungarian_welfare_system_19902013.pdf.

⁶ See <https://hclu.hu/en/articles/hungarian-government-must-suspend-and-redesign-deinstitutionalisation-projects-affecting-2-500-people-with-disabilities>.

2.2. LEGAL FRAMEWORK

Hungary has ratified the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol establishing an individual complaints mechanism at the Committee on the Rights of Persons with Disabilities. In this way it formally recognizes the rights of persons with disabilities in accordance with international obligations. However, in many regards Hungarian law does not comply with the CRPD⁷ and for example in 2012 the Committee noted with concern that persons with disabilities ('limited mental capacity') might be deprived from their right to vote according to the Fundamental Law, even though only in a judicial proceeding.⁸ The Hungarian also permits the full deprivation of legal capacity and accompanying guardianship. Despite international criticism, the Constitutional Court found it was constitutional.⁹ Supported decision making, although introduced, seems to be of lesser importance currently.

As for the rights of disabled people to care it is worth noting that Hungarian law does not really use the term 'care' as such, but rather 'health care and medical services'. When it comes to the rights of care-workers the law does not spell out labour rights of care workers but rather provides a lot of detail and conditions on the entitlement to the care allowance.¹⁰

The ban on discrimination against disabled citizens was established by the Constitution of 1989. The Social Welfare Act of 1993 (1993. III. törvény/law) made it mandatory for local authorities to provide home care for a maximum of four hours a day and to provide meals for persons over 60, financed by the central (national) budget. Depending on the number of residents, the provision of so-called pensioners' clubs could also be mandatory. The Act also unified social services, defined the nursing service as home help provision and established the category of those people who cannot provide for themselves and need assistance.

The 2/1994. (I.30.) law defined home help provision as a form of care that enables independent living, and meets the needs of the entitled persons in their own living environment. Eligibility was enlarged and age was not the only criterion as the service became more a question of health and social need than age. This law defined what counts as home care: the provision of hot meals, shopping, help with personal hygiene, dressing, making the bed, cleaning, washing etc. In special circumstances it allowed for care provision longer than four hours a day.

In 2003, on the eve of EU accession rights were further strengthened. The 2003 legislation gave the right to equal access to health care, social services, rehabilitation and work opportunities to all citizens, and banned discrimination on the basis of disability, gender, sexual orientation, ethnicity

⁷ Hungary appears to not have submitted till now the 2nd periodic report mandatory, which would have been due in 2014. See

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29.

⁸ This is a positive change from previous rules which declared an automatic disenfranchisement. However, after the condemnation in the case *Alajos Kiss v Hungary* from the EctHR, this was changed in the Fundamental Law. Still the current system means that most people with mental disability have to turn to courts, convince the judge and get their voting rights reinstated.

⁹ 11/2014. (IV. 4.) AB határozat.

¹⁰ See <https://net.jogtar.hu/jogszabaly?docid=99300003.TV>.

or religion. The modification of the social law in 2003 set out new groups with respect to home care: the concept of the elderly appeared, the category of psychiatric patients, people with disabilities, and the category of people who need care due to their health condition. The 2007 law does away with the different categories and offers the possibility for home care for those whose health condition demands this.

A national strategy for the social inclusion of disabled citizens was endorsed in 1999. A dedicated unit dealing with Equal Opportunities for Women and Men was set up within the Ministry of Social and Employment Affairs in 2000 and a consultative body with women's organizations was established in the same year. The Equal Treatment Authority was established in 2005 to enforce and implement the Act of 2003 and provide legal remedy for those experiencing discrimination. However, as reported by scholars and human rights watchdogs (for example, Majtényi 2009; HCLU 2013; GWI 2013), improvements in daily practice remained limited. Roma and disabled jobseekers continued to face discrimination in all areas of life, including employment and access to public services (for example, Sik and Simonovits 2008).

As with many other countries of Eastern and Central Europe legal regulation in Hungary has placed the burden of eldercare on the family and the Family Law Act has for a long time made it compulsory for families to provide care for their older relatives. Up to 1986 all elements in the formal eldercare system were given the pejorative adjective 'social'. Admission to a residential home was available only for the poorest older people dependent on a means-test to prove that their families were not able to support them. Residential homes were called 'social homes' which meant very poor infrastructure and appalling conditions such as 8–16 persons in one room, inadequate lighting, lack of basic hygiene, etc. For these reasons, people generally wanted to avoid sending their parents to a social home, but despite this, these homes had a waiting list of five or six years. Day care also had the pejorative 'social' adjective (social home help, social club for older people). All the institutions that bore this stigma also struggled with quality problems and over demand. Although the quality of the services improved, the system of eldercare services has continued to struggle with quantitative problems right up to the present.

The cash-for-care scheme, the name can be misleading, as it refers to quite a different set of relations from the ones in developed welfare states such as Denmark, The Netherlands etc. (care allowance or alternatively called nursing fee) in Hungary is restricted to family members (a spouse, a registered partner, a cohabiting partner, an affiliated relative, an adoptive parent, a step parent, adoptive parent, stepfather and foster parent, and step-brother or sister, a registered spouse, a relative and a relative of a registered spouse, and a spouse's spouse etc.)¹¹. A so-called (basic) care allowance/nursing fee (ápolási díj) means a small financial contribution for family members who provide in home care for (i) a severely disabled person or (ii) a permanently ill person who is under 18 years. The care allowance, which varies between 29800- 54100, is unable to cover the minimum subsistence necessary. There are three tiers of care allowance: in 2018 the basic care allowance was 29 500 HUF (short of 100 EUR), the second, so-called increased sum was 44 250 HUF, and the third category meant 52 810 HUF, a bit less than 200 EUR. These sums also implied a 10% pension contribution as well. The caregiver is not allowed to work more than four hours per day outside the

¹¹ 1993. iii. law 41. § (1).

home.

Act III of 1993 on social care and social administration, Art 40 et seq. The law does not spell out labour rights of such caregivers, but provides a lot of details and conditions on the entitlement to cash-for care.¹² A family member nursing a disabled or seriously ill family member is entitled to the care allowance if the recipient of care meets three out of four criteria (unable to wash or dress without assistance, to use the toilet alone, to move around indoors without an aid, or to eat without assistance), the care is provided 'full time' and the state of the recipient is certified by a body of medical experts. The time spent providing such care counts towards pension entitlement and a 10% pension contribution is deducted from the benefit. Any member of the family can perform this type of long-term care not requiring special qualifications. The amount of the benefit is only one third of the minimum wage. In 2018 this meant 29, 800 HUF (approx. 100 EUR), the highest sum being 54.100 (approx. 180 EUR). Out of 53 thousand people who receive the care allowance most of them are women in their 40s and 50s. Most of them care for their multiply, seriously disabled children and have spent their entire days on care for decades. The state does not recognise this type of care as work. It counts towards the pension but if they are ill for more than 45 days the state, the national insurance system, stops paying their health insurance.

2.3. RELEVANT AVAILABLE NATIONAL DATA

The number of people aged over 65 with some disability in Hungary (and Latvia) is the highest in the EU plus Norway (Büttl, 2018). One indication of the poor health is the proportion of disability: 10%, (in comparison in Lithuania, Slovakia and Romania 6–8%) (Mandl et al. 2006). One of the basic reasons for giving up work is deteriorating health; the figure for sickness, state of health and disability is already high (41.2%) among those aged 50–54 (KSH 2007a). Health problems preventing people from working or inducing them to leave the labour market appear in a relatively early stage of the life cycle; the dividing line can be drawn above 50 years, particularly in the case of men (KSH 2007b: 43).

The great majority of older people (70–80%) have been cared for by the family, or their family in conjunction with other care, mainly by retired women over 55 years (Hungarian Maltese Charity Service/MMSZ 2009 survey).

The number of persons receiving home care increased threefold between 2000 and 2012 (from 40,212 to 125,281). The net result was an upsurge in the number of recipients of care per carer: from 4.3 elderly persons per carer in 2000 to 7.3 by 2011 (Hungarian Central Statistical Office/KSH 2012, Table 7.3). In 2015 53 980 people used the care allowance.

¹² See <https://net.jogtar.hu/jogszabaly?docid=99300003.TV>.

Counties	Population	Number of care allowance users	Number of care allowance users/ 10,000 people
Budapest	1 744 665	5 014	29
Baranya	373 984	1 913	51
Bács-Kiskun	516 892	3 561	69
Békés	355 199	2 573	72
Borsod-Abaúj-Zemplén	674 999	4 595	68
Csongrád	407 389	2 470	61
Fejér	419 506	1 879	45
Győr-Moson- Sopron	450 318	1 603	36
Hajdú-Bihar	539 507	4 346	81
Heves	303 503	1 582	52
Komárom-Esztergom	300 677	1 083	36
Nógrád	198 392	1 750	88
Pest	1 220 748	5 942	49
Somogy	315 512	2 097	66
Szabolcs-Szatmár-Bereg	561 379	5 128	91
Jász-Nagykun-Szolnok	383 489	3 232	84
Tolna	227 996	1 387	61
Vas	254 580	1 140	45

Veszprém	349 007	1 154	33
Zala	279 623	1 531	55
Total	9 877 365	53 980	55

Source: Táarki Social Research Institute Inc. May 2015

There are clear differences among the better-off and poorer counties and. The capital city has the lowest number accounting for ten per cent of care allowance recipients while counties in the North-East (the poorest) have the highest number of care allowance recipients and small localities account for 40% recipients. Seventy-four per cent of those who receive care allowance are women, most in their 40s and 50s. Twenty-five per cent are younger than 40, and only 11% are older than 60. Sixty-three per cent of those who receive care allowance are between 40-59, the median age being 47 (Tátra, 2015:20).

Seventy-one per cent of those who do care work left the labour market to be able to do so. Eighty-three per cent of those who receive care allowance do not work. Eleven per cent have regular work while 5% have irregular jobs working once or twice a week.

Individual income	Care allowance beneficiary	Adult population
0-47 000 HUF (47 000 HUF = 145 EUR)	61%	20%
47 001-80 000	27%	20%
80 001-100 000	7%	20%
100 001-130 000	3%	20%
above 130 000	2%	20%
Total	100%	100%
Average individual income	50 334	90 788
Median individual income	40 000	90 000

Táarki Social Research Institute Inc. 2014 (in Büttl, 2018).

At a maximum of 145 EUR a month, the care allowance in Hungary is one of the lowest in the region. (Romania 270 EUR and care is recognised as work, Slovakia 425 EUR, the Czech Republic 576 EUR, Croatia 435 EUR, Poland 333 EUR). Sixty-two per-cent of those who receive the allowance do not have any other income source and the median income of those on care allowance is half that of the adult population.

Due to lack of funds 40% of local governments are unable to meet even basic obligatory services. The demand for home help is twenty to thirty times greater than supply. Furthermore, it is limited to a maximum of four hours a day and restricted to minor tasks that do not require health care training. Weekend service provision where it exists, functions extremely poorly. Both counts indicate that the system is unable to provide long-term intensive care. Health insurance will finance intensive home nursing for a maximum of 14 days so offers a solution only for acute health problems. In addition, only one per cent of those over 60 were able to use this service. As a consequence of all of the above there is a significant demand for residential and nursing eldercare services. While there are new non-profit and for profit institutions emerging, this has only slightly reduced the gap between supply and demand. Some five per cent of people aged 60 and above live in such institutions, financed by the health care or the social welfare budget.

The pension reform (1998) introduced with claimed aim to increase the sustainability of the pension system raised the retirement age first to 62 and later to 65 years. This measure aroused great resistance among women as they had to carry out family and care tasks in addition to their work, now for another extra three years, and as a result a new type of early retirement was introduced: advanced pension. Consequently the proportion of those receiving pensions stabilised at around 30% of the population (HCSO 1990–2007 Hungarian Central Statistical Office).

Already struggling with a slowdown of the economy starting in 2006, Hungary was hit hard by the financial crisis: GDP fell by almost 8% between 2008 and 2009 and has been stagnating ever since (HCSO - Hungarian Central Statistical office, 2012). At the same time, total government expenditure on social protection was cut from 18.6% in 2009 to 17.8% in 2010 and further to 16.1% in 2012 (Eurostat 2013), and 14.3% in 2018, respectively (Eurostat 2018). While most high income countries have increased social spending in real terms since the outbreak of the crisis, Hungarian governments have cut spending by reducing both the amount of and access to cash transfers and cutting the budgets of service providers (ILO 2010). The Socialist government of 2009, which held a one-year mandate to handle the economic crisis, froze the nominal value of family provisions and social assistance, abolished the thirteenth-month pension and tightened the behavioural conditions of social assistance in 2009. The succeeding Conservative government went further by decreasing the nominal value of social assistance, abolishing early pensions and reducing the duration of the insured unemployment benefit from nine to three months in 2011. The post-2010 developments entailed paradigmatic reforms of nearly all areas of the welfare system.

Since the change of political system in 1990, census figures show a net migration of 200,000 in 2001 (Hablicsek 2008), with most of the migrants 'ethnic Hungarians' coming from the Hungarian-inhabited regions of neighbouring countries (HCSO 2008). According to Péti and Szabo (2017) 78% of the migrants from the neighbouring countries arrived between 1985 and 2011, with 88% of these coming from Romania. Citing Tatrai et al. (2016) the article predicts a likely increase in the arrival of Ukrainians. (Péti and Szabo 2017: 348) There are no research data on undocumented migrant people

working in care (Széman, 2012) but it is known that the employment of invisible migrants is a part of long-term strategies of family care.

In principle families can meet the care needs of their elderly frail relatives from the labour market. The private care sector offers a wide and constantly expanding range of high quality eldercare services, ranging from a few hours of home care to residential nursing. The monthly fee charged for nursing homes is equivalent to 80-85% of the average wage with additional charges for costs such as medicines and extra services like physiotherapy which can be important for the elderly. The total monthly fee to be paid for nursing can be equivalent to or more than the average wage. Thus one obstacle to the development of private services for long-term care is only a small group of upper middle and middle class and people with savings can afford them, particularly given fall average wages following austerity measures. Some middle-class people are able to use market services for a short period, but over the long term even with the combined financial efforts of family members including the older person's pension such services consume their savings (Széman, 2012). Private nursing enabling the older person to continue living at home is beyond the reach even of the middle class: home nursing is charged on an hourly basis and five hours of nursing a day for one month costs, apart from short periods, this type of care. Firms providing eldercare on the legal market often charge exorbitant prices. These are justified through reference to high wage-related costs including social insurance contributions, though in practice care workers receive a very low wage, often less than half the fees and further reduced by income tax, and the profit margins can be high.

Care in general, whether it is eldercare, care for people with various disabilities, home help or nursing, is often provided by women working in the informal labour market. Informality appears as advantageous for both the worker (with the drawback that she is excluded from health care and social insurance) and the person or family pays approximately 4-6 EUR/1000-1500 HUF per hour, which is only half what a formalized care/home nursing service would cost.

3. ETHNOGRAPHY

3.1. CARE MAPS

First care relationship

Anna/care user – Paula/care giver (24-hour care, 10 days)

Anna/care user – Maria/care giver (24-hour care, 10 days)

Paula/care giver – Maria/care giver (the two carers sometimes meet when their shifts end and one arrives to replace the other, and speaks on the phone)

Anna/care user – Anna's daughter – Zsuzsa/mediator/contact person between care user and care giver

Zsuzsa/mediator/contact person – Paula/care giver (first had a face to face meeting some years ago, now spoke on the phone when the need for a care worker arose)

Zsuzsa/mediator/contact person – Maria/care giver (first had a face to face meeting some years ago, now when the demand for a care giver arose she contacted Maria)

The first care relationship consists of an elderly frail woman, aged 93, two women care givers, both pensioners in their mid-sixties, and the mediator, the person who helped the researcher gain access to this household, pseudonym Zsuzsa. I used the pseudonym Anna for the elderly woman. Paula and Maria were the two care givers, pseudonyms were used in their case as well.

This care relationship I observed was a new care relationship. When I first arrived it was barely two weeks into a new situation when Anna was not living by herself any more but employed care givers in her home to look after her. Zsuzsa, the person who helped me gain access to this household thought it important for me to be able to see a new care relationship where the different participants were still adjusting to their new situation. Zsuzsa stated several times that it was just natural that she would ensure that I did my observation in a safe and pleasant environment. She was the gatekeeper, my access was dependent on her, and based on our discussion which was more than one hour long, she put me in contact with Anna's daughter, a woman in her sixties. I reached her by phone and some three weeks later, she introduced me to her mother. I did not have Anna's contact number, it was through her daughter that I could communicate my plans. After that initial contact I did not meet Anna's daughter any more, except very briefly, but it was her who gave me a ride to Anna's place the first time I went to visit her.

I still recall the moment when I first stepped into the house and met Anna who was slowly coming towards me reaching out her hand. She welcomed me warmly, her mischievous smile on her face, which I came to think of as a reflection of her attitude, an openness to the world, curiosity and grace too, which I think, defined her as a person to a great extent. Then I met Maria, the care worker who came from a town in the Eastern part of Hungary. She knew about me coming, although I could not talk to her in person before this. She welcomed me as well and put me immediately at ease with her straightforward and kind manner. When I introduced myself and told her a bit more about what I was doing and which institution I was working for, she raised her eyebrow at the name of the CEU. She told us, (Anna was there too), that she was a Fidesz supporter¹³ and said she hoped this was not a problem. Anna assured her that this was not a problem and remarked that she was happy she could do something for the CEU, that she hoped she could make a small contribution to normality, to a more peaceful world, to a world which was less rabid and mad. This was how my visits to Anna's home began.

Second care relationship

Aron/care user – mother (meeting daily)

Aron/care user – Shiatsu therapist (meeting every second week for a 60-minute session)

The second care relationship consisted of a 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. As a first step I contacted Aron's mother through a friend and she talked to

¹³ The governing party in Hungary at time of writing.

her son about this research. Aron quickly agreed to being part of this research. He was as much curious as what a researcher would do as I was about him and was looking forward to this peculiar journey. He later half-joked that I might be also part of the material, 'the raw data' of his next theatre play. He was a gifted artist, who wrote, acted and directed plays. I was not only observing but I was being observed, which while it startled me, also calmed me, as it made me think that perhaps the relation was therefore more balanced, more equal. It assuaged to a certain extent the uncomfortable feeling that I was an intruder cannibalising people's lives and that I was there only concerned with their vulnerabilities, aspects of the self that most people would rather hide. It was as if I was saying: 'Show me your dependency'. But what I actually got would again and again fly in the face of this. Aron at one point told me that maybe he was not the right disabled guy for this research, 'The right character' as he put it.

This research was granted ethical approval by the Central European University' ethics committee. I first sought permission from the care users, and subsequently the care workers. In the first case, the two care workers in the elderly person's household clearly tied and subordinated their consent to Anna's decision. My presence was regarded as one of the tasks they encountered in the house. In the case of the young person with disability, both the physical therapist and the mother consented to the research in agreement with the young man. Once I gained the initial consent to observe the care arrangements in practice I tried to preserve the trust I received upfront. How could I navigate that thin line between observation and intrusion? My presence was already some sort of interference, a disruption to the by then functioning care relation. The other challenge that I encountered through the initial phase was the fact that my facilitators wanted me to observe success stories where disabled people finally became independent and needed no more care or assistance. They could not really understand why I did not show enough interest, or appreciation in their eyes, in those cases where individuals had succeeded in making themselves totally independent on such care relations.

3.2. MOBILITY AND AUTONOMY

In the first household the care receiver, Anna, was a frail adult elderly woman in her early nineties who, while still very weak when I started my visit, could move slowly around the house and who continued to work on her books and manuscripts. When I started my field visit she needed 24 hour assistance, hence there were two care givers (Paula and Maria, respectively) employed who worked for ten days in a row. Later when her condition improved only one carer continued to work every second week with Anna subsisting with no assistance every other week. Despite her advanced age of 93 Anna was still lecturing and doing scholarly work.

In the second case, the care user was a young man with physical disability, Aron (also a pseudonym), who could walk anywhere albeit with difficulty. If longer distances were involved his mother would give him a lift. He used several forms of physical therapy, and I obtained permission to attend his weekly Shiatsu therapy session, performed by a Shiatsu physical therapist.

The care receivers I observed were a frail elderly person who spent her days in the house with just short walks around the house and a young person with physical disability who led an active social and professional life outside the home as well. The care givers themselves had varying degrees of

mobility. Their capacity to move about was not constrained by physical frailty but by what their work demanded and allowed for and what their *habitus* drew out for them. For the Shiatsu therapist it was far more convenient if the clients came to the school where she worked than her visiting her clients. For Aron's mother it was important that she had her own car and thus she could quickly get wherever she needed to including the lifts she would give to her son. The two care givers who were working with Anna had slightly different attitudes to leaving the house of their employer. Paula, who was from Budapest, seemed to be more ready to take a walk in the village, not only to buy something in case she needed it, but just for a simple walk, whereas Maria was more comfortable with staying in the house and looked forward to going home where she could socialise and take walks if she wished. Anna's house was in a village about an hour from Budapest using public transport. The house was perched on a small hill to which meandering streets led. This was a twenty-minute walk from the centre with a church and a park. If the care workers needed to buy something (the weekly shopping was done by one of Anna's children), or to take a stroll they could walk to the village square or take a minibus which ran every half an hour. They could also go for a walk in the woods nearby, which locals would often do.

3.3. ACCESS

In both cases access was facilitated by my Central European University (CEU) affiliation. When looking for households open to participate it became clear that while this would close some doors to me it would open others would. I began by wanting I started with the understanding (see Széman 2012, 2015) that private care in Hungary had been mainly provided informally by mainly ethnic Hungarians who are citizens of Romania, or Ukraine or Serbia and proposed to observe Transylvanian care workers (Transylvanian Hungarians are a minority ethnic group who are citizens of Romania whose mother tongue is Hungarian). I contacted a friend who runs an NGO and she suggested some people I could approach including a retired woman, Zsuzsa (pseudonym), a pensioner and who worked one day a week for an NGO. She had been connecting elderly people in need of care with care workers for around thirty years. I had two long interviews with her. She grew up not knowing she was Jewish, and found out about her origins much later in life. While working as a social worker she met some people working in organisations that supported Jewish people and as a result started to help elderly Jewish Holocaust survivors find appropriate care. When I asked if she was working with Transylvanian Hungarians, her colleague, who was present during the first half of our talk, claimed that Transylvanians were not suitable for this kind of work, because they did not have the skills and they were too rude. Later, Zsuzsa too voiced her reservations about Transylvanian Hungarian care workers. She told me that many of the elderly people she helped find care came from formerly prosperous bourgeois Jewish families who before the War would employ as servants gentile people from villages or who had recently arrived in the capital city looking for work. The care relationships she knew about, she facilitated followed the same pattern, Jewish people who employed gentile care workers.

I also contacted an acquaintance active in the Transylvanian Hungarian diaspora who I knew to be in contact with families employing carers from Transylvania. She readily agreed to help having in mind some households where I could follow care relationships. However, labour market changes following the 2008 economic crisis seemed to result in fewer Transylvanians coming to work in Hungary, preferring to go to Western or Northern Europe. Furthermore, I had started this research in

the period around the 2018 Hungarian national elections during which time CEU became the target of the right-wing government. It was accused of furthering foreign interests and serving 'foreign agents', an allusion to George Soros, the founder of the university, whom the ruling establishment singled out as the main culprit for Hungary's and Europe's migration crisis. My contact explained that these political concerns about the CEU might cause problems for access. Sure enough, after several attempts she informed me that the household she had had in mind would not participate because of the current attacks on the CEU. However, in some cases my affiliation had precisely the opposite effect. Both of the homes I accessed agreed in part to show their support of the CEU.

I made contact with the second household through first approaching the mother who was from the very beginning open to this research and who put me in touch with her son, the care user. He in turn introduced me to the physical therapist. Here my request to observe a session, which must have been quite unprecedented, was accepted although it was received rather suspiciously.

In both cases friends and acquaintances helped me access to the two households. It was through friends and their acquaintances that I could claim the sort of trust that such a research environment and practice requires. All through the initial phase of trying to find the households willing to have me for a week-long visit I was dependent on a chain of people whom most of the time I did not know but who agreed to talk to me at the request of friends, friends of friends and acquaintances. These tenuous links to these chains of trust could any time break or cease to bring any results as happened to some of the initial leads I followed.

The care relationships I came to observe were in well-off, middle-class households. Both care users were well-connected, able to work and to spend their days doing what they found important and what they believed in. They were not bed-ridden, and were enthusiastic users of music and theatre. During my initial talk with Zsuzsa who eventually helped me find one of the households, she assured me that she would find a good place for me, which for her meant a place where I would not need feel uncomfortable or in danger. It would have been futile to insist on putting me in contact with a more 'average' household.

The care users relied on informal care and managed to secure the kind of live they wished to live. The family circle and the larger social circle, the networks that could be mobilized, that they came to inhabit and secure for themselves, and which by no means was independent of the wider social, political and economic context, allowed them to have a degree of autonomy in their lives that not many people can enjoy. Both belonged to the a middle-upper-middle class. However, the sets of care relations involved were quite different. One required 24-hour live-in care which in practice covered daily tasks like cooking, cleaning and keeping order in the house. The other was restricted to more limited intervals, such as a one-hour physical therapy or a lift by car on the part of the mother. The physical therapy had been ongoing for two or three years by the time I came to observe its choreography whereas the care relationship in the case of the elderly person was a relatively new situation.

Both care users resorted to the special invisible care market and paid for the care workers they employed. The elderly woman relied on her pension supplemented by her savings. She had retired in 1986 and found it deeply unjust that the pension of those who, like her, had retired long ago was not enough to enable them to live comfortably. While she could pay for the care workers for a short while,

and after after her condition had improved she was able to continue with only one care worker for alternate weeks she saw many of her friends struggling to meet ends meet, and was sorry she was not in a position to help them. She found it deeply problematic that, as she saw it, the state rewarded the more prosperous, while punishing those more vulnerable and who were more in need. She felt the state should look into problems far more deeply and deal with the real questions. She felt she had no say in what the state was doing, she had no voice that the state would listen to. She believed that the state served the interests of a very narrow circle, and not of those who need it.

The young man with disability said he did not make use of any state support other than his state provided monthly public transport ticket. He relied on his parents and more recently supplemented by his own income but this was not enough to enable him to lead the kind of life he lived. His parents' support and his mother's preparedness to take him whenever and wherever he wanted was clearly acknowledged and valued.

The two care givers in Anna's household were both in their mid-sixties retired, living alone with independent children. One came from one of the more prosperous villages close to Budapest, where wealthier Budapest residents sometimes move for the greener space and the fresher air. The second came from a middle income district in Budapest. Both said they still felt physically strong and open enough to accept the challenges care work brings. Both had decent pensions, and stated that they were not dependent on the additional income they earned through care work bought but that it allowed them to help their children, live a more comfortable life, and save for their own future care. They told me that care work brought something additional to their lives, it meant learning about new customs, meeting new people, and kept them more open.

3.4. THE HOUSE ON THE HILL: WHERE EMOTIONAL BONDS END. FIRST CARE RELATIONSHIP

Anna's house was built next door to one of her children only three years ago and so it still felt and looked new at the time of my visit built right It seems a house right out of a fairytale: Small and wooden, and close to the nearby forest it struck me as a warm and welcoming place. The house had been constructed according to Anna's specifications. There was a small porch and a narrow paved path around the house that meant Anna could take a daily stroll outside even when it rained. She did this at least once a day, even when she was very weak. There was a small hall as one stepped in the house, and to the right the bathroom used by the care workers and to the left the care workers' accommodation. This was a small and comfortable room, with a bed, a wardrobe, a television and a desk. Just before the living room, to the left, was a small pantry. The living room was a warm and welcoming place with light lacquered wooden floors. Older, beautifully carved bookcases and new ones made of light wood, purpose built for this house lined the walls. These were deep bookcases with two and three rows protected from dust by glass panels. The room also housed a piano, an old writing desk, a lot of CDs of mainly classical music. There was also a small round table with chairs around it, and on them the beautiful cushions that one finds in Hungary and in Transylvania with traditional patterns sewn in mainly red at times combined with blue, green or black. These cushions are handmade artisan objects, often gifts from mothers and grandmothers hailing from different times, different places and different mores. The small kitchen was attached to the living room occupying the same space yet a bit detached from it. The next room was Anna's combined bedroom and study room

with a bulky writing desk covered with books, and smaller bookcases, a tiled stove, and large windows overlooking the backyard. From here a terrace door allowed her to step out into the garden which had two or three much cherished fruit trees. Next to this room there was Anna's separate bathroom. The arrangement of the house allowed both the care user and the care workers a great degree of privacy, with separate rooms at the opposite ends of the house. When the care giver in residence finished her tasks, after breakfast, or after lunch, or dinner she could withdraw into her room to rest, read or watch TV, or speak on the phone with their children, or they could take a walk in the village or in the nearby woods.

When I arrived Anna and the care workers were about two weeks into this arrangement. The latter were familiar with some of the tasks and the village, but were still learning about some of the requirements and the area. The care givers tasks were mainly focused on keeping the house tidy and ordered, cleaning and helping with the cooking. Usually Anna would wake up first and come into the kitchen. She did not need any help at that stage. She would then go back to her room, read and later have the morning bath. During this time the care worker would come to the kitchen and prepare the table for a light elevenses, which they would eat together and discuss lunch and what needed to be done that day. After this Anna would retire to her room and rest or work. They would have lunch together around 1 pm, chat a bit, and again Anna would return to her room while the care worker would clean the table, start the dishwasher and clean the kitchen, then going to rest. Occasionally when there was something they were both interested in watching on the television, Anna would sit down with the care worker in the care worker's room and watch TV.

Apart from the tasks that had to be done the care workers were free to spend their time as they wished. They could use the kitchen whenever they wanted, they could have a coffee or tea, and they could eat whatever was in the fridge or the pantry. Both workers chose to eat the same meals as Anna who was following a diet appropriate for her age. The ten-day live-in arrangement was an adjustment from Anna's originally proposition of two weeks as Maria had originally wanted to work alternate weeks. This would have ben to hectic for Anna and thus the ten day period was settled on.

The atmosphere in Anna'a home was jovial, friendly and quiet and calm all at the same time. The first day I arrived Anna let me in and welcomed me. She approached me smiling and shook my hand. She was a bit amused and puzzled, and this feeling lingered throughout my stay. The care worker was busy in the other room cleaning. As a visitor-researcher I was also an intruder, at least this is how I often felt, and I felt awkward about asking to go and look at what the care worker was doing. I hesitated; anyway, it was not the cleaning itself that I needed to observe, I was telling myself, but the interaction between the two people, between the care user and the care giver.

Their days had a particular rhythm and shape. There was a routine, a specific regularity to their day, and often this was not about their interaction, but about doing things separately, on their own. The day was organized around allowing Anna to proceed with her work. This meant that the household had to be run by the care workers. They would encounter each other several times a day mostly when they sat down to have their meals or when the tasks of the day ahead needed to be decided or when some fine-tuning was taking place, a negotiation as to what to do next and how to do it best. Their talk was like any other discussion when people politely and sensibly interact with one another, their roles were balanced, with Anna careful and sensible when making her requests and the care workers kindly complying with those requests.

I regularly sat at the table in the living room. I observed that Anna was content to be left on her own, to have her elevenses on her own and contemplate. On my arrival one particular day there was some soup on the stove, and Anna stirred it from time to time. Maria, the care worker appeared from the other room and asked her how to clean the top of the wardrobe. Eventually I asked Anna whether I could go to the other room where Maria was cleaning. Maria said she did not mind my presence when I asked if I could observe what she was doing. I asked if I could help somehow but she declined. We chatted a bit and I sensed some sort of mild irritation, dissatisfaction conveyed by her tone and her words as well, with having to clean almost every day when the flat was already spotless, with no sign of dust anywhere, let alone dirt. She made remarks about there being too many things, books and notebooks, lying on the table. I was surprised as everything was neatly placed, and not at all randomly lying around. Anna later told me that she was upset sometimes because since she had moved into this new house she did not know the precise location of each book. She had notebooks in which she had a list of all her books with their new location, with some books still waiting to be included in the list. Maria remarked that at her place there was nothing on the table, and she pointed to other objects as well in the room that she would not have liked to see there, for example, a newspaper holder on the floor, and remarked that when she cleaned she was constantly dodging the objects on the floor remarking that the house was spick and span and she did not really understand why she still needed to Hoover every day. She commented on the bathroom too, again saying there were too many things lying around. She said in her house she had nothing on the floor not even in the bathroom. She was eyeing a small table at the foot of the bed covered with books and papers, neatly arranged, and wondered if she needed to clean it. When I suggested she could ask, she said she would not, and told me that if Anna wanted her to do this then she would let her know anyway, but she would not ask. I sensed irritation with the situation, maybe with my presence as well and later she asked if this was the last day of my visit.

After a while Anna knocked on the door, peeped in and asked if Maria had finished the cleaning of her room and of the bathroom, which happened every day at the same time, while Anna was taking her elevenses. When she was told that the cleaning of her room had been done Anna thanked Maria. I noticed that she said thank you after every request and after every task completed by the care workers, however small. She did it with tact, it was not forced and it often came with an element of humour. When the cleaning in her bedroom had been completed Anna immediately collected her notebooks from the kitchen table and retreated into her room. Maria then cleaned the kitchen table, putting away the tea cup, and setting the table ready for the lunch.

When I asked Anna about how she found this new situation she gave me a quite compelling assessment. It struck me how sensibly she approached the entire situation. She explained that she was doing her best to make the care workers' stay as tolerable for them as possible as she was aware of how difficult it was for them to find themselves in someone else's home for days at a time performing mundane tasks that one usually would do at home for oneself. She said it was important for her to be consistent and predictable in her requests and not to act on a whim, but in a manner which was helpful for the care givers to follow. She also said that she often did not insist on certain things, that she tried to let go of certain expectations. This, however, could not prevent the care providers sometimes feeling impatient or irritated about some of the requests.

The tasks that the home care workers performed were often repetitive activities, which, at times looked strange or pointless to them, yet they did them nevertheless, and in the way they were

asked even though they would probably do them in a different way at home. There were many small gestures, from humorous quips, to small silences, and some sharper asides that enabled the care givers to both 'inhabit and reproduce the sensorial and social worlds of their clients' (Buch 2013:638) and to express their frustration. As Buch shows, carers' mundane acts of care formed the basis that allowed the care user to continue living as one was used to (ibid.). This meant, for example, cleaning as often as required, cooking as required, observing the right place of each object in the house, and attending to each request no matter how small or insignificant may seem to the care giver. There prevailed and emerged a set of 'moral hierarchies between persons', 'the sense that some people's needs and desires ought to take priority over others' (ibid.). The care workers were there to help Anna. Anna's needs were at the centre of their daily interactions. There was a hierarchy which was experienced and justified on a day-to-day basis. The justification was in terms of a job that had to be done and for which they had been hired.

While there was a moral hierarchy which prioritised the care user, both care workers found it important to tell me that they were not dependent on the care work they were doing. They had pensions and the income earned with this work was an extra money. This allowed them to either save for their own care in the future, for travels or for helping their children. The fact that they were entitled to a pension was one of the ways they signalled their moral worth and dignity. They also emphasised their sense of self-worth by stating that they were in a position to choose the person they worked for, and if they found the arrangement unsatisfactory, or the demands or the situation disturbing they would quit or not accept the position in the first place. They also spoke to me about their previous experiences as carers and were proud to tell me that they were still in touch with some of the families they had worked for, and sometimes they were even invited on holiday by the children whose parents they had looked after and who had already passed away. They were proud that these bonds were still strong even after the care relation proper had long ended. The care givers had a social, cultural and economic capital amassed during years, and the combination of these shaped their position in the current care relation.

The current care relationship was about making order, running a household as the care user would do it if she were still able to do so. Anna did not really need looking after as she was not a bed-ridden seriously ill person. Yet, even though Anna favoured privacy and solitude, the care workers knew they needed to be alert and aware of her every move in case something happened – as happened on one occasion when the ambulance had to be called at night. Their continuous presence was a matter of precaution, which required a 24-hour readiness. Anna expressed her frustration at having to spend her savings on care as her pension was not sufficient for this. Although one of her children lived next door, and the other a few hundred meters away only, she was adamant about not burdening them with her care needs.

As Paula, one of the care givers put it, at the core of this kind of relationship is the ability of care workers to 'adjust'. The word used in Hungarian is translated as pliancy, adaptation, conformity, deference. For her care in this particular case was about doing what they were asked to, even if one did not nod in agreement all the time. Paula, who had previously worked in a children's home, spoke in light terms about these conditions. She had a good sense of humour and she used it when expressing her slight disagreement with what Anna suggested. They understood each other and appreciated honesty and straightforwardness. It was easy to like Paula. She was intelligent and funny and at the same time outspoken, features that Anna very much appreciated. They had an amusing way of talking

to one another, sometimes joking at my expense about their roles as care giver and care user sometimes calling each other by these names. When Anna did not need a carer every week any longer, it was Paula she asked to remain.

Paula once described this care relation as an interaction requiring constant discussion about the tasks ahead together without wanting to force your will upon the other one. She expressed her appreciation of Anna and of her way of dealing with people. It was during her stay that Anna at times went to the room reserved for the carer and sat down to watch with her a movie or a quiz on TV. Paula acknowledged that she was surprised and pleased at the same time.

Thus as well as making order in the house, home care was also very much a question of personality. It was important for Anna to have a care worker that she liked. She needed an emotionally intelligent person who would act with tact and understanding. While the work was about doing the tasks that Anna could not complete by herself anymore because she was too weak, care work was also about two people interacting with one another as equal, where kindness and reciprocity were as much needed as the physical strength to run a household.

When Maria's stay came to an end, the way she departed deeply hurt Anna. She found it unjust as the care giver left without properly saying goodbye. According to Anna, Maria was paid on Sunday and was to leave the next morning. It had been agreed they would say good-bye at 6.30am, the small minibus taking her to the railway station stopping just 100 meters from the house. However, a friend of Anna's had arrived from Germany and Maria asked her if this friend could give her a lift, a request which Anna declined saying that she could not ask her guest who had just arrived to take Maria to the railway station. Anna said Maria took offence and left without saying goodbye as they had agreed upon the day before. Anna was clearly upset and told me she found this behaviour deeply hurtful, saying that a bond, an emotional attachment had developed and that she did not deserve this kind of behaviour. Maria's account differed. She said she knocked on Anna's door in the morning to say goodbye but there was no response so she thought Anna was still asleep and left without seeing her. According to Paula, Maria was not aware of the pain she had caused and she bore no grudges against Anna. The two carers at times communicated on the phone, interaction that I did not observe. They spoke with respect about each other. I wonder if there was some sort of competition between them, an unspoken anxiety whether one's work was as much valued as the other's, and whether Anna's decision to go on with one care giver may have caused Maria pain, or a feeling of not being appreciated. Some months later I found out that Anna was on her own as Paula too had left unexpectedly, apparently for a better paid job with another household. Anna was deeply hurt and told me she never wanted to hear about care workers again.

3.5. WORKING MOTHER: SECOND CARE RELATIONSHIP

I had my first meeting with Aron in one of the popular ruin-bars in Budapest's party district. He was a regular guest there. He would also often have his lunch at this place. Many of the people who entered the bar would greet Aron or come to our table and exchange a few words with him. The waitress who served us knew that Aron drank with a straw. Without asking she brought it and left the straw on his plate. As a toddler he was diagnosed with ICP, infantile cerebral palsy, a brain disorder that affects muscle tone and motor skills which in his case was later compounded with osteoporosis. When I met

him, Aron was in his mid-twenties and despite his disability he led a full life. He was writing, directing theatre plays, acting and he recently featured in a quite successful feature film.

To be able to live the life he wanted meant resorting to different physical therapies, careful to strike a balance between physical activity and exercising. When we met, Aron was combining several types of physical therapy alternating between different types of massage and weight lifting, all in all four different exercise forms. His mother would take him to most of these therapies except for the ones he had at home. I was given permission to observe a session of Shiatsu therapy. The therapist was employed by a Shiatsu school but Aron was one of her private clients. She had previously worked as a conductive teacher at a children's hospital. Conductive Education is an educational system for children and adults who have motor disorders of neurological origin such as cerebral palsy based on the work of Hungarian Professor András Pető. However, after a while she found that kind of work too demanding and too strict to accommodate other alternative therapies she was interested in. The Shiatsu therapy was a way for her to further develop professionally.

Before the therapy session started, Aron and the therapist, warmly greeted each other like people who know each other for a long time and are happy to see each other. The therapist inquired about Aron's past week and asked if he was physically feeling good. She arranged the mattress and the extra supports Aron needed. Aron's room was a tiny one in a flat that he was sharing with another person. The room was small and narrow, it contained a bed, a desk and a bookcase. The remaining space on the floor was not too spacious but the mattress could fit in for this purpose. I sat on the chair in one corner and waited. Apart from one or two short questions about whether particular points hurt him or not, the session happened in utter silence. From the first moment it was clear that both people in the care relationship Aron, the care user and the care giver, the therapist were used to one another, that both knew the exact choreography of the session. This meant that Aron could relax and lie back, close his eyes and trust the therapist. The point as I understood and as I could see of this type of therapy was the inner harmony and peace that it could bodily convey and establish in addition to physically relaxing the muscles. Aron was wearing loose clothes as did the therapist. She was very careful in touching him, placing and adjusting his limbs at times asking him to turn or sit up. There was not much that I could do except for observing what was happening in front of me. The most helpful thing for me to do was to keep as still as possible and maintain the silence. The sound of my pencil was at times the only sound apart from the distant sound of one or two cars passing by under the window. This particular session lasted sixty minutes. It was a brief encounter in a long-term therapy. Aron had been using Shiatsu therapy for more than two years on a biweekly basis. The two of them had known each other for quite some time by now. While apart from the therapy itself the time the two could spend was very short, before and after the session there was a friendly chat and it was clear that the therapist was familiar with her client's life and interests and the ups and downs of his physical condition. While they were friendly with one another I could also sense that the therapist has a tight work schedule that she needed to stick to, and the session was precisely 60 minutes long. Aron paid for this service, although I did not get to see this interaction. Before she left, they agreed on the next meeting in two weeks' time.

When I met Aron he was totally self-sufficient at home. His flatmate did not need to assist him. The usual courtesy and friendly gestures applied here as well. When, for example, she would make a coffee or tea she offered it to Aron as well. Aron did not cook, he mostly used the microwave to warm things. His mother brought cooked meals at times, and he would often have lunch in the pub nearby.

While he could write and rehearse some roles with colleagues at home, he was often out and about, and it was not easy to accommodate my visits. Unlike Anna, for him moving about in the city was central but travelling longer distances was one of the biggest challenges for Aron. I was surprised when he acknowledged that walking was a painful activity which he constantly needed to consider when deciding to get somewhere. His keen sense of humour helped him laugh at the indifference of the transport authority. He described vividly but also with a lot of irony and humour, - he was after all a storyteller - the simple act of taking the tram and reaching a seat that was being offered to him. This was a real challenge. The handholds did not help him much, he stated, as their placement was not designed with a mind to disabled people. So he had to decide. Was it worth wading his way through a crowd of people and by the time he reached the seat it was already time to get off? Or was it better to stand where he was and spare himself the physical pain and unnecessary fuss of moving? The best thing, of course, would have been if the closest person sitting would offer their seat. If they knew what passed through Aron's mind, the effort it took him to stand and walk, that would have been an ideal situation. When I asked him about what could possibly improve disabled people's lives Aron spoke about empathy, closeness, and education, about more people being more familiar with the difficulties disabled people encounter. As he put it: 'It is not enough that my friends know about my needs. It is not my friends who sit on the tram'.

Aron has been using some sort of physical therapy since he was a toddler. His mother has been his principal carer for more than twenty-five years. She did not think of her unselfish care as work, while agreeing with the current petition started by several organisations representing disabled people to have the care of disabled family members legally recognised as work. Her care had been made possible thanks to a high-earning husband. She was the one to arrange the care needs of her son and track down the therapists all through these years, about whom she spoke lovingly. At the beginning she had no choice but to try and find people who could help her son herself. She was less positive about the formal support they had received, especially during the early years. She complained that she had been let down by doctors, who could not tell her, or could not direct her to places where her son could receive help. She appreciated the support of carers (mostly physical therapists) and praised their attitude for not restricting Aron too much in his movements. She said that trust was an important element in all these care relationships, and she remarked that they had been lucky with all the physical therapists they have worked with. Both she and Aron were exceptionally calm and open. I could not but note that they spoke of people who provided care to Aron along the years in loving and appreciative tone.

Jane was clearly proud of her son. She recalled with warmth how popular Aron was with his schoolmates, and Aron as well at one point remarked to me that it was easy for people to get on well with him. That was my experience as well. When I talked to them about the cash-for-care policy their reaction was one of amazement and amusement. When I later spoke again to Aron, he confided to me that they had talked about this with his mother 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's care could be remunerated seemed to them quite bizarre. At the same, yet happening at a distance from their household, advocacy groups were mounting pressure on the government with the goal to have the home care provided by family members to their disabled kin legally recognized as work. Home care not yet recognized as work in the summer of 2018 meant that home carers of severely disabled or ill family members still had no right to the national minimum wage, there were no limits on their working

hours and they had no legal right to holidays or any time off. In case the carer fell ill and were to be hospitalised, after 45 days the social insurance would not cover their medical expenses any longer. Most people, except for those directly affected, were unaware about the legal and working conditions of home care. This to a large extent contributed to the work of home carers remaining largely invisible. It happened within the hidden abode of the private sphere, and those who could speak about their daily work were prevented from doing it as they did not have the time, the means to leave the cared ones at home and appear in public and inform the public about what home care was about. The summer of 2018 saw a series of public appearances, demonstrations and petitions, covered mainly by the small online media, and led mainly by three advocacy groups “Lépjünk, hogy Léphessenek Közhasznú Egyesület”, “Csak Együtt van Esély (CSEVE) Csoport “ and “aHang”. The aim was to draw society’s attention to the work and plight of home carers and their families, and thus apply pressure on the government to have the 24-hour home care of severely ill or disabled family members recognised as work. As it stood carers of disabled family members were entitled to a care allowance (or nursing fee), which could barely reach two hundred EUR at most. In August the opposition wanted to convene a special parliamentary session to discuss the care allowance and the housing situation of those saddled with huge mortgage debt but the ruling party failed to show up. In the absence of the required majority the session had to be suspended. As on other occasions the government was dragging its feet and circumventing, sidelining the most critical advocacy groups, and when it finally agreed to consider the matter it barred from discussions those critical groups and invited only the organisations that were more compliant with it. On 17 October 2018 the state secretary of Families and Youth announced that the care allowance of those caring for their children would be 100 000 HUF, around 300 EUR, starting from the 1st of January 2019. While this meant a considerable increase, it, in fact, applied to only 34% of families caring for their loved ones (see Büttl above). Only those families that cared for a child (of any age) were entitled to this increase. Other families where a parent, or a spouse etc. was being cared for, were not entitled to this increase.¹⁴

Aron and his family had never applied for the care allowance. What they had used was the child care benefit, then the childcare allowance, the family allowance and the disability benefit. When I talked to Aron and his mother, it emerged they did not know about the care allowance. As Jane saw it the income her husband earned working 12 hours a day, made it possible for her not to go back to work but stay at home and attend to the needs of her children. She admitted they could afford to do this without this allowance. At the beginning this may have emerged as an option but now she did not remember anymore why they eventually did not apply for the care allowance. She had been the main caregiver for most of Aron’s life. It was only recently that her main role as caregiver had been slowly undergoing change as her son attained and demanded more autonomy for himself and for his mother. He wished his mother could build a life of her own that did not revolve around his care needs. They did not live in the same house any more, but she was still ready to help out, she was virtually on a continuous stand-by. If Aron had to get somewhere, and taking public transport would be too long, or taking a taxi was not an option, he could call her and ask for a lift, which Jane would happily do. He used to have a taxi-driver whom he would pay in advance a certain sum and then he could call him

¹⁴ The cared person is the carer’s parent in 34% of the situations, the carer’s child in 34% of the situations, the spouse or partner in 12% of the situations, the sibling 5%, foster parent or great grandparent in 5%, the grandchild 1%, the parent/child/sibling of the spouse 4%, the spouse of the parent/child/sibling 3%, and other 2% (Tátrai, 2015).

when it was needed. These days it was still his mother who would give him a lift on most occasions. And 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 this was the only time during the day when mother and son met and when they could talk a bit about their days? One day Aron got really angry. His mother had been fined as she was parking in a parking place reserved for disabled people. When this happened Aron was not with her. He found this situation unjust. As before he expressed his frustration with the authorities, about their lack of consideration.

4. CONCLUSION

Several European welfare states have introduced a mixture of social rights and work-related rights into the legal framework of care work performed by family members for their senior relatives (Pfau-Effinger et al., 2011). The “de-familialising” role of welfare-state policies on long-term senior care has entailed a formalization of care for senior citizens supported by welfare states. (Esping-Andersen, 1999; Leitner, 2003; Lister, 1995). These policies signal the recognition of what Taylor-Gooby (2004) aptly characterized as “new social risks” since care obligations towards family members can mean part-time or fulltime exit from the labour market, which in turn means a potential loss in income and decrease in social security entitlements. Many cash-for-care schemes have been introduced with respect to ameliorating these new social risks. However, in Hungary, the care allowance (or nursing fee) introduced with Act III of 1993 on Social Administration and Social Benefits does not address these new social risks, which means that families are left on their own to solve their care needs in the way they can.

As the above presented case studies show all the people involved from the care users to care givers had deeply personalised or rather “familialized” strategies where the capacity of self-reliance was deemed to be of utmost importance, complemented or primarily built on the support of the family. Individual strategies of families were the norm when solving the care of their elderly or disabled family members. Their everyday struggles were isolated and individual struggles that they had to address as individuals. They did not and could not think of themselves as part of a larger social group able and with the right to formulate claims vis-à-vis the welfare state, while all of them came to name solidarity as an important aspect of a good society. So did they value self-sufficiency. When thinking about justice and injustice, Nancy Fraser cautioned us about the norms, significations, constructions of personhood that bar certain groups from parity of participation in social life, how they become embodied and institutionalised at the same time, ‘materially instantiated in institutions, in social actions and embodied habits, and ...in ideological state apparatuses’ (Fraser 2000: 114). And while self-sufficiency and autonomy are conditions that one can reasonably wish for, and my interlocutors, particularly the care users found it central in their lives, if its possibilities are realised as part of and left to only individual or familial strategies, strategies dependent on their financial situation, anyone who finds oneself short of these strategies, and finances, will find themselves barred from participation in social life all together. The state provision in these instances as depicted above are inadequate as they do not recognise the place, extent and value of care in society.

The (welfare) state should be able to and be willing to step in and remedy various forms of injustice. But as both cases show this ability and intention is absent with respect to home care in

Hungary, demonstrated not only by the continuous diminishing public spending on social provision (Eurostat 2017) but also by the more immediate everyday life experience of the care workers and care users observed in this research. The retrenchment of the welfare state can be captured thus in the understanding, expectations and demands those involved have and the claims that they make or don't, and the ensuing practices, strategies. For example, the care relationships observed showed the absence of the belief that the state is willing to remedy their situation. The state in both households was regarded as a distant entity. It was one's profession, calling on the one hand and on the other hand the family and friends, a narrow circle that made it possible for the care users to have the care they needed. And within this circle it was primarily women who provided care, who shouldered the burden of providing care on a daily basis, attending to the minute and micro needs, urgencies and wishes, with husbands and fathers and sons being there as well albeit in a different role and capacity, one step removed from the daily household routines and micromanagement needed to sustain these households. The care users' favourable class position and their profession, arts and education, cushioned them and made it possible for them to live a meaningful and rewarding life despite their disability and frailty due to old age. The two care givers caring for Anna were both retired. Except for Aron all the other participants had their experience of the welfare state shaped by what was once the one-party state under János Kádár and the post-1990 governments. Based on this they did not see themselves in a position to make claims towards the new welfare or rather workfare state nor did they regard the state as ready to accommodate, or listen to their demands. They were resigned to having to solve their own care in old age by themselves with the savings and the pension they had. Their claims, often voiced as complaints, were formulated and voiced in private. Art could help if one was an artist, one could ridicule power, if not, one could express their frustration with the injustice they encountered among family members and friends.

The (welfare) state hardly appeared for care givers and care users as a source of help and support, as a reliable arbitrator, embodied in and enacted through a series of institutions and its representatives willing to listen to and address the complaints, questions, problems citizens struggled with. If pressed, both care users and care givers acknowledged that the state must have responsibilities, and should have the capacities to intervene. However, their every day practices and long term care-strategies were about to make sure that at the end of the day they need not depend only on the rather poor services provided by the state. The two care givers were proud of their pensions, but both remarked that they were complementing these with the money earned from the care work with a view also to their future care needs. As pensioners they were more or less recognised by the state, but not in their capacity as carers. Their worth and recognition as pensioners derived from their years of employment. This has been recognised by the state for decades, and by far not equally among pension recipients. Their work as carers, however, was much more invisible, but for them and the care users. What I found, hence, were individual coping strategies, solutions that depended on families and friends, and strangers paid for the care they provide. This was compounded with the often half-acknowledged belief that the state was either indifferent to the plight of those in need of care or resourceless when it comes to private and public care alike, and one is in a better position if one does not need rely on the formal public care system or on the care allowance (nursing fee), for example.

Both the care givers and care users alike lived and experienced justice and injustice in the context of the home at an arms' length from the state. Within the private sphere that the household meant the understanding was that home care meant a special kind of work, where emotional

investment, attachment, and trust played a defining role. Within the private households observed the daily acts of recognition could happen in the spirit of fairness and reciprocity, tolerance and sensibility. Injustice was also experienced in light of attachments and bonds formed when these bonds were broken. This experience, and the related meaning of justice, confined as it was to the sphere of the household, however, appeared as if it had been severed, so to speak from the rest of society, from the welfare/workfare state. None of my interlocutors had ever used the term “welfare” state. They always spoke about the state.

For justice to work, the experience of care encompassing both the care givers, the care users and the close relatives, that is, an entire network of care, should be part of the knowledge that the state has and on which the latter is willing then to act upon, upon listening to and together with those affected. This could be a welfare state, indeed. A step forward would be in general for the Hungarian state to recognise the importance and omnipresence of care in society. As a more immediate step it could recognise not simply the existence of home care, both formal and informal, but also its utmost importance and accordingly value it, incorporate it and regulate it. More directly, with respect to the care allowance the state should not only increase the sum but recognise home care as work - as some of the respondents of this study and the above-mentioned advocacy groups argued. How to implement this recognition should be based on a dialogue that is ready to accommodate the expertise and experience of, for example, cash-for-care schemes that already exist abroad, paying attention to their shortcoming as well, and adapting them to the Hungarian context. The recognition of home care as work is not devoid of problems as Betlen (2018) pointed it out. Caring relatives and non-relatives face lower social security entitlements (e.g. sickness, unemployment, pensions and other periods of non-labor-market activity) and their social rights are reduced in comparison to those in formal employment. The status of employee would entail that the caregiver is entitled to all social rights (e.g. access to health insurance, unemployment benefits, sick pay, vacations, pension and work accident coverage). The governmental decision on October 17, 2018 to increase the care allowance in case of families who care for their children (adult and minor), that is, affecting only 34% of those who are on a care allowance does not only deny the recognition that the status of work could confer on home care, but it also creates divisions and punishes certain families for not caring for the right people as if caring for parents, spouses or all the other care users, were of less worth. If care users received enough monetary benefits, for example, in the form of some scheme of cash-for-care, care users could be in the position to choose the care givers and could pay them, reward their work as they deserve. If care work, covering informal care as well, were acknowledged and recognized, recognition and regulation based on prior consultation and negotiation with affected groups, then, for example, care users, as the above presented case showed, would not be left out in the cold, either, if a care giver suddenly received a better offer and decided to leave the care user. Commodified private home care, including informal one, and currently this is by far the most widespread in Hungary, while it happens within the private sphere of the household, needs to be recognised for what it is and what it means for society at large. For this to happen, the state needs to assume its responsibility, which means that care work and all those involved in it should not be forgotten, their knowledge and experience should be incorporated so that nobody would be left out in the cold in the future.

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