

A CASH-FOR-CARE SCHEME TARGETING CHILDREN WITH DISABILITIES
IN TURKEY: PARENT/CAREGIVER PERSPECTIVES



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2018

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IN TURKEY: PARENT/CAREGIVER PERSPECTIVES

Thesis submitted to the

Institute for Graduate Studies in Social Sciences

in partial fulfillment of the requirements for the degree of

Master of Arts

in

Social Policy

by

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2018

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Parent/Caregiver Perspectives

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DECLARATION OF ORIGINALITY

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- I am the sole author of this thesis and that have fully acknowledged and documented in my thesis all sources of ideas and words, including digital resources, which have been produced or published by another person or institution;
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ABSTRACT

A Cash-for-Care Scheme Targeting Children With Disabilities in Turkey: Parent/Caregiver Perspectives

A cash-for-care scheme targeting mainly families with at least one disabled member has become the central policy response to the care needs of persons with disabilities in Turkey's welfare regime. This thesis explores how beneficiaries perceive this program by focusing specifically on caregivers of children with disabilities. In-depth semi-structured interviews were conducted with 16 caregivers of children with disabilities—four primary caregivers who have been receiving cash-for-care at the time of the research and four primary caregivers who have lost their benefits—in Istanbul's Atasehir and Sultangazi districts between February and May 2016. The research reveals that although cash-for-care scheme has been widely welcomed by the informal caregivers, it has been perceived by the caregivers as a symbolic financial aid instead of a wage in exchange for their informal care work. In addition, cash-for-care beneficiaries that were included in this study perceive this scheme primarily as a financial support for poverty alleviation rather than a cash benefit in order to meet the special needs of their children with disabilities. While the introduction of a targeted cash-for-care allowance has signified an extension of state responsibility in social care, this thesis concludes that the program functions not as a care support scheme but as a social assistance scheme for the very poor.

ÖZET

Türkiye’de Engelli Çocuklara Yönelik Evde Bakım Aylığı Politikası:

Bakım Veren Ebeveynlerin Yaklaşımı

Hane içinde en az bir engelli bireyin bulunduğu ailelere yönelik evde bakım aylığı politikası, Türkiye’nin refah rejiminde engellilerin bakım ihtiyacına karşılık temel politika olmuştur. Bu tez çalışması, hane içinde engelli çocuğu bulunan ve onun bakımı için evde bakım aylığı alan bakım verenlerin, bu nakit programını nasıl algıladıklarına odaklanmaktadır. Bu amaç doğrultusunda 2016 yılının Şubat ve Mayıs ayları arasında, İstanbul’un Ataşehir ve Sultangazi ilçelerinde bir saha çalışması yapılmıştır. Evde bakım aylığı alan dört kadın ile önceden evde bakım aylığı alan fakat araştırmanın yapıldığı dönemde aylığı kesilmiş olan dört kadın ile her iki ilçede olmak üzere toplam 16 bakım veren kadın ile yarı yapılandırılmış, derinlemesine görüşmeler gerçekleştirilmiştir. Araştırma sonucunda evde bakım aylığı politikası enformel bakım verenler arasında oldukça kabul gördüğü halde, bu nakit programının bakım verenler tarafından enformel bakım emeğinin karşılığı için verilen bir maaştan ziyade sembolik bir finansal yardım olarak görüldüğü ortaya çıkmaktadır. Bunun yanında bakım verenler, evde bakım aylığı politikasını engelli çocuklarının özel bakım ihtiyaçlarının giderilmesi için sağlanan bir destekten çok, öncelikli olarak hane içindeki yoksulluğun azaltılmasına yönelik verilen finansal bir destek olarak algılamaktadır. Evde bakım aylığı politikası, sosyal bakım alanında devletin sorumluluğunu artırırken; bu tez çalışması mevcut politikanın engellilere yönelik bir bakım desteği olarak değil, toplumun en yoksul kesimi için bir sosyal yardım mekanizması olarak çalıştığını ortaya çıkarmaktadır.

ACKNOWLEDGEMENTS

First, and foremost, I would like to express my gratitude to my thesis advisor, Professor Volkan Yılmaz, for his engagement and patience through all processes of this master thesis. From the first day I entered his lectures and throughout the thesis, Mr. Yılmaz has enlightened my way both as a student and as an individual with his intellectual contributions and endless encouragement. Without his inspiration, I would never have been able to get into the field of disability studies. Also, I would like to thank to Basak Ekim Akkan, who encouraged and guided me to study on the issue of social care. I really appreciate Prof. Biray Kolluoglu and Prof. Pinar Uyan Semerci for participating in my thesis committee and for their invaluable contributions.

There are not enough words to express my gratitude for my family. I would like to dedicate this thesis to my parents, İpek Avşaroğlu and Mustafa Avşaroğlu for their hard work that helped get me to where I am today. Without their endless support, it would be very difficult to finish this thesis.

Finally, I would like to thank warmly to my best friend Ezgi for making life more entertaining and not letting me alone in this journey. Also, I am very grateful to my significant other, Cem, for his ability to make me feel better when times were tough. I am so blessed to have such good friends like you.

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CHAPTER 1

INTRODUCTION

“If nearly 13 percent of Turkey’s population is disabled, why can’t we see them when we go out?”

Ever since I started to conduct a research on disability, my friends and family members have always asked this question to me. Studies on disadvantaged groups within the context of social policy, especially persons with disabilities, are limited in Turkey. But the growing literature relies on the social model of disability, which emphasizes that disability is socially constructed. The social model explains the exclusion of persons with disabilities from all domains of life on the basis of the social obstacles rather than the bodily or mental differences of persons with disabilities. This approach paved the way to an understanding of problems that persons with disabilities face from a human rights perspective, including social rights.

If we do not come across persons with disabilities in the public sphere, where are they and with whom? According to Morris (1996) and Crow (1996), the social model should challenge the distinction between public and private sphere, as this distinction makes the persistent inequalities in the latter are generally invisible. At this point, the social environments of persons with disabilities and how their relatives have been involved in their social care activities have emerged, but faded into ignorance. Within this framework, the main objective of this thesis is to examine how carers of persons with disabilities in Turkey who benefit from the cash-for-care scheme, perceive this program. The thesis is based on a quadrilateral of disability,

care, gender and social assistance policies within the Turkish context.

The main research question of this thesis is: “How do caregivers of children with disabilities benefiting from the cash-for-care scheme perceive this program?”. Sub-research questions are as follows: How does cash-for-care towards persons with disabilities affect the lives of caregivers of disabled children? What are the outcomes of this policy in the eyes of beneficiaries? What do beneficiaries think about the program design? How and to what extent the cash for disabled care program meet the needs?

Recent policy implications have shown that cash-for-care schemes have become central in social care policies in various countries (Glendinning and Kemp, 2006; Ungerson and Yeandle, 2007; Rummery, 2010). Turkey is not an exception to this global trend. However, the rationale behind the cash-for-care programme in Turkey is different from the programmes in European countries. Turkey’s ruling Justice and Development Party’s (AKP) strong emphasis on family in its social policies is reflected in the area of cash-for-care policy towards persons with disabilities as well. An at-home care allowance was introduced with the Law on Disabled People ratified in 2006 (Republic of Turkey Ministry of Family and Social Policies, 2006). However, as the policy lacks universal coverage due to its targeted character, the cash-for-care beneficiary candidate has to meet the some requirements in order to be eligible for cash-for-care. First, the impairment level of the person with disabilities has to be over fifty percent, which would indicate that the person is in need of care. Second, the average income per capita within the household of the disabled person must be lower than the two-thirds of the minimum wage (household income/the number of individuals in the household=average income per capita). This means that the eligibility for this scheme is defined on the basis of income, and it

targets only those facing income poverty. To sum up, the policy implementation of cash-for-care is a part of the familialistic social solidarity within the domains of social care and social assistance mechanisms in Turkey's welfare regime (Buğra, 2002).

This law draws on the reasoning that the institutional capacity for caring for those with disabilities remained insufficient (Altuntaş & Atasü-Topçuoğlu, 2016). In fact, other scholars found that since this law was passed, cash transfers to disabled individuals and their families have become the largest item in the public spending on disability policies (Yılmaz and Yentürk, 2012).

Although the cash-for-care is a programme that targets persons with disabilities that have met the eligibility criteria, I have taken “children with disabilities” as the smallest unit of my research. The reason for this choice is that many of the studies have demonstrated that children with disabilities have more needs and assistance requirements than elders with disabilities. Therefore, I have used the term “cash-for-care scheme targeting children with disabilities,” instead of “cash-for-care scheme targeting persons with disabilities” throughout the thesis.

However, my hypothesis is that, while the means-tested design of the current at-home cash allowance has failed to bring the social care issue to the public sphere, it has also failed to meet the special needs of children with disabilities, as it has been perceived as supplementary income to help meet the basic needs of the household, as the programme targets only those facing income poverty. This thesis argues that the caregivers perceive the program as a symbolic financial aid instead of a wage in exchange for their never-ending “informal” care work and care support.

This thesis contributes to the existing literature in the Turkish context by providing a discussion on the evaluations of a social policy programme beneficiaries,

with a specific focus on the cash-for-care programme. Most importantly, this thesis sheds light on the experiences of informal caregivers who are receiving cash-for-care and providing care for their children with disabilities.

1.1 Research methodology

1.1.1 Cases/Unit of analysis

I selected two districts in Istanbul, Ataşehir and Sultanbeyli, to recruit respondents for my study. According to Erdoğan's¹ study on the average income of districts in Istanbul as identified by 2007 real estate prices, he categorizes districts into one of five income groups: 0-500, 560-830, 830-1,160, 1,160-2,020 and 2,220-6,410 Turkish liras, based on the monthly income per capita. As the cash-for-care scheme is targeted and income means-tested, only people who are above the official poverty threshold are expected to benefit from cash transfers. Therefore, it would be exceptional to see families who are receiving cash-for-care in districts in which the average income level is more than 1160 Turkish liras. I selected Sultanbeyli and Ataşehir, as the average income of former district is between 560 and 830 Turkish liras and the average income of the latter district is between 830 and 1160 Turkish liras.

Reaching out to beneficiaries of the program was not an easy task. My strategy was to find participants by using my contacts in district municipalities.

When I asked two municipalities whether they had “disability centres”, I learned that

¹ This study was prepared by Mr. Emre Erdoğan for a project named “Devlet İlköğretim Okullarında Ücretsiz Öğle Yemeği Sağlamak Mümkün Mü?.” It was published in the book which has the same title, that is written by Aysen Candaş, Başak Ekim Akkan, Sevda Günseli and Mehmet Baki Deniz in 2011, and published by Open Society Foundation.

the Sultanbeyli municipality has a disability centre called “Disability Coordination Center” but Ataşehir municipality did not have one. In Ataşehir, I contacted the Social Assistance and Solidarity Foundation of Ataşehir, which has a legal mandate to run means-testing procedures, in order to reach out the caregivers who are receiving cash for disabled care and those who have lost the eligibility to receive cash-for-care. They told me that the majority of the parents who have disabled children are receiving cash-for-care, but that there are also a significant number of people who are not eligible anymore to receive the cash-for-care for various reasons although their socio-economic status is very low. The existence of a municipal disability centre was an important indicator for me because it would be easier to reach the beneficiaries of at-home cash allowance through visitors to the center. Thus, I concluded that the Sultanbeyli district was an appropriate case to study the cash-for-care scheme for children with disabilities within the Turkish context. There are two reasons why I chose the Ataşehir district. First, Ataşehir residents are generally in an upper middle income group compared to Sultanbeyli residents, according to Erdoğan’s study on the average incomes of Istanbul’s districts. Despite this fact, there is a considerable number of households that are receiving cash-for-care and households who have lost their eligibility to receive cash-for-care. However, due to the declaration of state of emergency in Turkey, the institutions from Sultanbeyli did not want to cooperate with me in terms of providing the names and addresses of the cash-for-care beneficiaries within their district, on the reason that this data is sensitive and should be kept confidential. As a result, I decided to choose Sultangazi, instead of Sultanbeyli as my second district. According to Erdoğan’s study, Sultangazi is comparable to Sultanbeyli in terms of the level of average income and also, it has a municipal disability centre. Although I thought that

the presence of disability centres would be an advantage for me in terms of reaching the beneficiaries of at-home cash allowances, they refused to provide me with contacts due to confidentiality concerns.

My other strategy was to cooperate with the city councils, “mukhtars” and rehabilitation centres in two districts in reaching out to caregivers. As a result of my efforts, my second strategy finally worked and I received a list of beneficiaries of at-home care allowance in two districts. In Sultangazi, I found the caregivers benefiting from cash-for-care program through my personal contacts, a rehabilitation centre employee in the neighborhood. In Ataşehir, I found the beneficiaries with the support of the Ataşehir city council and the district mukhtars.

1.1.2 Sampling

Because I chose the cash-for-care policy for children with disabilities as the case for my research, the primary data source of my research was primary caregivers of disabled children benefiting from the cash-for-care scheme. In line with the conceptualization of Della Porta and Keating (2008), I used a homogeneous sampling based on the same socio-economic status in both Sultangazi and Ataşehir. However, while my research’s main domain is the cash-for-care scheme, I interviewed two groups: caregivers whose have been receiving cash-for-care and ones who have lost their eligibility to receive benefits.

The caregivers that I interviewed were chosen randomly from the lists of beneficiaries obtained from Ataşehir City Council, the mukhtars of the İnönü and Mustafa Kemal neighbourhoods in Ataşehir and the mukhtars of the Gazi and Yunus Emre neighbourhoods in Sultangazi and a publicly-funded, private rehabilitation

center in Sultangazi.

1.1.3 Methods

Semi-structured interviews were conducted with the primary caregivers who have been receiving cash-for-care. The reason I chose semi-structured interviews instead of structured interviews was to encourage the respondent to talk about issues that I had not envisaged and to enable a dialogue between the researcher and the respondent.

Conducting focus groups with primary caregivers of disabled children who have been receiving cash-for-care would have been helpful to determine how group dynamics would affect people's perception of the program. However, such for primary caregivers to attend the focus group meetings, care support would have been required.

In-depth interviews were conducted with 4 primary caregivers in Sultangazi who had been receiving cash-for-care at the time of the research and 4 primary caregivers who had lost their benefit. Similarly, in-depth semi-standardized interviews were conducted with 4 primary caregivers in Ataşehir who were receiving cash-for-care at the time of the research and 4 primary caregivers who had lost their benefit. The main aim of this selection was to find out if a cash-for-care scheme makes a difference in care arrangements in households that benefit from this scheme.

Table 1. In-depth, Semi-standardized Interview With the Families of Disabled Children

District	Receives cash-for-care	Number of respondents
Sultangazi	+	4
Sultangazi	-	4
Ataşehir	+	4
Ataşehir	-	4

Although I would like to have interviewed both the mothers and fathers of the children with disabilities, I could not find fathers at home during the home-visits. Therefore, I was obliged to conduct these interviews with 16 women who were primary caregivers of children with disabilities.

Detailed profiles of the caregivers will be discussed in the beginning of Chapter 4. The overwhelming majority (n=13) of the respondents were married; only three were divorced. Also, while only two caregivers had been working informally as cleaning ladies part-time, the rest of the caregivers identified themselves as “housewives” when I asked about their employment status. While two carers reported that they were involved in paid employment before they started to receive a cash allowance, the rest stated that they had not been in paid or unpaid employment before. The number of the people living in households I visited varied from two to eleven. Table 1 shows the profiles of the caregivers in the field study.

Table 2. Profiles of the Caregivers

	Distri ct	Name	Age	Marital status	Person s per househ old	Employe nt status	Did she work before?
Still receiving cash-for- care	Ataşehir	Ayşe	38	Married	4	Housewife	No
		Fatma	40	Married	6	Housewife	No
		Meryem	35	Divorced	3	Housewife	Yes
		Sena	32	Married	3	Housewife	Yes
	Sultangazi	Songül	52	Married	4	Housewife	No
		Ayten	45	Married	6	Housewife	No
		Arzu	35	Married	11	Housewife	No
		Hacer	43	Married	9	Housewife	No
Cash-for- care has been cut off	Ataşehir	Hatice	39	Married	3	Housewife	No
		Leyla	48	Married	5	Housewife	No
		Mine	35	Divorced	3	Cleaning lady (informal)	No
		Nalan	53	Married	6	Housewife	No
	Sultangazi	Serra	59	Married	5	Housewife	No
		Tuba	40	Divorced	4	Housewife	No
		Zuhal	51	Married	8	Housewife	No
		Nurten	39	Divorced	2	Cleaning lady (informal)	No

1.2 Outline of the chapters

The thesis continues with Chapter 2, which provides a literature review on disability, care and welfare. The chapter begins with a brief summary on the literature examining social care for children with disabilities in market economies and continues with a discussion on different cash-for-care schemes targeting persons with disabilities. After that, the outcomes of the cash-for-care schemes including the impact of at-home care schemes on the care arrangements within the households are discussed.

Chapter 3 examines the policy framework for social care with regard to children with disabilities in the Turkish context. The chapter starts with an analysis of the politics of care in Turkey's welfare regime and continues with Turkey's experience with disabled care. The cash-for-care scheme and its consequences in terms of gender relations and care arrangements are discussed.

Chapter 4 provides an analysis of beneficiary perspectives on the cash-for-care policy in Istanbul's Atasehir and Sultangazi districts. The experiences of primary caregivers with at-home care allowance are analyzed under five thematic areas: application, general attitudes towards cash scheme, impact of cash scheme, care arrangement in the household and spending arrangement.

Lastly, Chapter 5 discusses the implications of the field study with reference to the existing literature.

CHAPTER 2

DISABILITY, SOCIAL CARE AND WELFARE

2.1 The politics of social care

In “The Three Worlds of Welfare Capitalism” (Esping-Andersen, 1990), Esping Andersen categorized welfare states as liberal, conservative or social democratic, using an index of decommodification. However, Andersen did not include “gender” or “unpaid work” as variables in his research. In response, feminist scholars introduced social care, a “gendered” domain that generally involves “unpaid work,” as another core dimension of welfare state analysis.

There is no doubt that care work is gendered, generally resting on unarticulated but powerful normative assumptions about the acceptable role and value of care work as ‘feminized’ (and hence legitimately undervalued in market terms) and ‘private’ (and hence legitimately monitored by the state) (Lewis, 2002; Rummery, 2010). Daly defines care as the activities and relations involved in caring for ill, elderly and dependent young (Daly, 2002). She identifies care as a “complex social good”.

Daly focuses on the three frameworks that social care has developed. First, as a feminist concept, care deals with women and women’s roles as wife, mother or daughter, which are determined in the private sphere. The second issue in the conceptualization of care is an ethical dimension. It deals with the norms values that are involved in care, and these values are beyond the family and kinship. Therefore, care is a form of social capital and a public value rather than an intimate relationship between caregiver and care-receiver. Actually, this is what makes care a political

issue. However, what is perceived is that care is only a matter of creating and strengthening relations based on emotional bonds with children, partners and children (Geissler & Pfau-Effinger, 2005). The third concept is the treatment of social care by social policies and how social policies deal with the demand for and supply of care. Daly and Lewis claim that in the 1980s, when female participation in the employment rose visibly, there was a shift of responsibility from the state as provider of cash and care towards the family to the private and voluntary sectors (Daly & Lewis, 2000).

In this period, social care started to rely more on market relations. Therefore, scholars focus on the way in which social care lies at the intersection of public and private, formal and informal, paid and unpaid and provision in the form of cash and services. They understand the term “care” as labour, a normative framework of responsibility and an activity with financial and emotional costs that goes beyond the public and private boundaries.

A similar perspective was developed by Knijn & Kremer’s (1997). Their study highlights the dichotomies of care: paid versus unpaid, formal versus informal, private versus public. According to their study, the needs of care are provided in three domains, namely, services, cash, and time, but the provision of care differs from country to country, and it changes over time. The dichotomies of care have different policy implications, but their balance within the provision vary according to the government in power. Social policies are key factors that shape how social care is handled in specific countries. Social care policy choices in each country have a significant impact on the labour market, family and state. For instance, if the government provides cash-for-care benefits, this would affect the labour supply and demand in the long run. Therefore, all types of available care provision and policy

frameworks surrounding social care arrangements form the care regime of a country. Anttonen and Sipilä (1996) have examined social care regimes, focusing on the social care services in European countries. As a result, they came up with two social care services models: the Scandinavian model of public care services and the southern European familialistic care model. Bettio and Plantenga (2004) have taken the study a step further. In order to identify care regimes, they have focused on care provisions in Europe, both formal and informal arrangements, but they have also taken socio-economic causes and consequences of different care regimes into account. They found that “differences in the economic character and role of the family have made a major impact on the prevailing care regimes” (Bettio and Plantenga, 2004).

2.2 Caring for children with disabilities in market economies

The presence of a disabled child can have a significant impact on a household (Baldwin, 1985), resulting from the high costs associated with providing support for disabled children and the possible decreased opportunities for parents to secure employment due to childcare needs within the home (Read & Clements, 2001).

While one part of the literature on living with disabled children has highlighted the positive aspects of family life (Connors & Stalker, 2003), another part stresses potential restrictions on family life, including limited access to a range of activities, which has been found to be challenging for some families (Widdows, 1997; Dobson & Middleton, 1998).

On the relationship between child disability and poverty, most studies argue that disabled children are at higher risk of living in poverty and of facing social

exclusion than able-bodied children. The rate of income poverty is generally higher for persons with disabilities (Yeo & Moore, 2003; Emerson & Hatton, 2007). The fact that children with disabilities and households where they live in are significantly more likely to live in poverty also increases the risk of poor health, withdrawal from education, additional impairments and social exclusion (Brooks-Gunn and Duncan, 1997; Bradshaw, 2001).

Also, care that parents provide disabled children is generally more time- and labour-intensive than caring for a non-disabled child. Roberts and Lawton's (2001) analysis shows that the majority of children in their sample required extra assistance or supervision in multiple areas of daily life. In each of activities (washing, dressing, meals during the night and keeping occupied), more than 70 per cent of children needed extra help and, on average, each child needed extra help or supervision in the areas of daily life.

Glendinning's study with 30 caregivers (including children) also shows that there is a clear pattern of younger disabled people requiring a much larger number of special aids than those who were older (Glendinning, 1992). The evidence from this research shows that toiletries and cleaning materials, especially those related to incontinence, commonly require extra spending for children with disabilities. In this regard, the study points out that low-income families caring for disabled children face a higher spending burden than high-income families. With the combination of the extra costs of caring for a disabled children and living on very low incomes, the carers living at the lowest levels of social security benefits mentioned that they were simply unable to afford basic items such as warm clothes, heating and housing repairs (Glendinning, 1992). Among these households, "actual expenditure may fall short of the items or commodities which are needed" (Glendinning, 1992).

It is also worth mentioning that the majority of high-income families or carers have relied on labour-saving and time-saving items to ease the work while caring for their disabled child. These items include laundry appliances to ease the extra work involved in care-giving, dishwashers or freezers to save carers' time and effort in other areas of domestic work and extra televisions, radios and videos, which are thought of as more for the direct benefit of a housebound disabled person (Glendinning, 1992).

One of the biggest challenges of caring for disabled children in developed countries is the burden of care on the caregivers within the family. As Scott indicates, children with disabilities live disproportionately in female-headed households (2010), and mothers of these children shoulder a disproportionate burden of care (Cohen and Petrescu-Prahova 2006; Rogers and Hogan 2003). A number of studies have found that mothers of children with disabilities have lower labour force participation than mothers without disabled children (Breslau, Salkever, and Staruch 1982; Erickson and Upshur 1989; Porterfield 2002). According to Porterfield (2002), Powers (2003) and Leiter & Krauss (2004), mothers of children with disabilities are more likely to leave the labour force or reduce their working hours if they are in a formal employment. Glendinning's (1992) study also indicates that "the most common reason for deciding to stop work all together is the increasing amount of care which these carers were having to provide, and the difficulty this caused in also meeting the demands of a job" (Glendinning, 1992). Therefore, the literature shows that caring for disabled children has a significant impact on families, especially mothers, in terms of their employment status and their participation in the labour market, even they have an opportunity for alternative care instead of home-based care.

The “cash transfers for home-care” policies, as it is observed in the Turkish case, strengthens the prior policy implementation in line with the global trend by financially supporting mothers caring for their disabled children without providing them with care support. Research on Turkey and other countries demonstrated that the caregivers have faced different problems such as feeling insufficient, despair, excessive loneliness within the means of familial relationship, along with psychological disorders such as depression, anxiety or panic attacks, and physical disorders such as pains. Being isolated and having a relationship breakdown within the social environment are other effects on female caregivers who are receiving cash-for-care at home (Sloper & Turner, 1992; Altuntaş & Atasü-Topçuğlu, 2016).

Being a parent of a disabled child frequently necessitates support from a multitude of agencies and professionals. However, for many parents, especially for mothers, this experience is tiring, time consuming, and frustrating and can involve continuous battles for even the most basic support or provision (Read & Clements, 2001). This, coupled with problems associated with coordination and joint planning between agencies and professionals, can lead to disabled children and their carers becoming marginalized (Appleton, 1997; Department of Health, 1998). As the study of Roberts and Lawton (2001) confirm, “severely disabled children have considerable extra care needs in many areas of daily life, so parents want professionals to recognize this and offer explicit acknowledgement of the extra care they give their disabled children.” Some studies also demonstrate that the stress on parents caring for a disabled child has been increasing due to the lack of support from professionals and unmet needs for services (Baxter, 1987; Sloper & Turner, 1992).

2.3 Cash-for-care schemes for persons with disabilities: A comparison

Although the literature on the cash-for-care schemes in developed countries is extensive, the biggest weakness is that the vast majority of the research that compares different types of cash-for-care schemes is based on the cash-for-care schemes targeting the elderly rather than persons with disabilities. However, research based on the cash-for-care schemes in long-term care systems has been taking the care-receiver as an elder who has been requiring long-term support due to advanced age. Despite this, most of the literature has been defining these elders as “disabled”, so that the much research makes no distinction between elders and persons with disabilities.

Interestingly, experimentation with cash-for-care schemes is not confined to liberal welfare regimes (such as those in Canada and the USA) that have traditionally been more market-oriented in their approach to benefits and services. They have also been introduced in conservative welfare states (such as Austria and Germany), social democratic countries (such as Finland), and in southern European countries (such as Italy). While some of the countries that have introduced such schemes provide little in terms of home care services (such as Italy and Ireland), others provide extensive in-kind services for older and disabled people (e.g. Sweden).

When we look at the cash-for-care schemes in various European countries more closely, the evidence demonstrates that there are prominent particularities among them. First, the strict regulation of cash-for-care schemes has strongly influenced the “commodification of care” (Ungerson & Yeandle, 2007) as well as the development of specific forms of care work and informal care (Da Roit, Le Bihan, and Österle, 2008). Moreover, although there are some exceptions (Lundsgaard,

2005), researchers have tended to focus on cash-for-care schemes as specific policy instruments separate from more general long-term care policies.

Care work, whether paid or unpaid, is still overwhelmingly the responsibility of women in the UK, the Netherlands, Italy, France, Austria and the USA, according to Rummery's study (Rummery, 2010). Nevertheless, the employment status of women engaged in care work in different countries makes a significant difference in their life trajectories.

Timonen, Convery and Cahill (2006) argue that the motives for introducing cash-for-care programmes in the UK, Ireland, Finland and the Netherlands are similar, and include the following: to promote choice and autonomy, to plug gaps in existing provision, to create jobs, and to promote efficiency, cost savings and domiciliary care. Despite the similarity of motivations, the introduction of cash-for-care schemes has not radically transformed the care regimes in these countries. Their study on the cash-for-care schemes in the European context follows that the welfare states that can be described as neo-liberal and residual if they rely heavily on the means-tested payments and low level of social service provision. Therefore, in countries where there is lack of alternative forms of formal service provision, as in the case of Ireland, the cash-for-care might shift care provision significantly towards private provision and financing (Timonen, Convery, & Cahill, 2006).

Using Rummery's (2010) cash-for-care schemes by welfare typology—which has been influenced by Casey (2003), Esping-Andersen (1990) and Bettio and Plantenga's (2004)—I would like to discuss in detail the cash-for-care schemes of three countries: two from liberal/Anglo-Saxon welfare states and one from the conservative/continental European countries. The reason I chose two liberal welfare

states is that they differ in terms of their social care regimes. In doing so, I would like to explore the cross-country differences in motives behind, regulation, and implementation of cash-for-care schemes and situate Turkey in this picture. I will also present the gendered impacts of the cash-for-care policy in each country case.

2.3.1 United Kingdom

The Direct Payments (DP) system in the United Kingdom has its origins in the demands voiced by the disability rights movement for greater autonomy and choice. Compared to other cash-for-care schemes, the UK's direct payments scheme is a relatively regulated policy development which enables care users to buy care services from the regulated market and to employ their care workers or personal assistants in line with the UK employment law. What is important here is that, the government makes the necessary arrangements for the Direct Payment receivers, in order to spend the allowance on purchasing caring labour and related services rather than spending it on household needs and finances (Yeandle and Stiell, 2007). The main motive of the policy is to enable care users to make their own choices about when, how and from whom they receive care services.

The community-care provisions of the National Health Service and Community Care Act 1990 removed eligibility for DP for people aged 65 or more (because of concerns about escalating costs), but in February 2000, the entitlement was restored, and since April 2003 under the Health and Social Care Act 2001, local authorities have been obliged to offer DPs for all with care needs based on a needs assessment. Therefore, since 2003, local authorities have been obliged to offer DP to all those eligible, but take-up varies greatly by local authority (Timonen, Convery, &

Cahill, 2006).

However, while these seem to be generally welcomed by care users, the limited availability of caring labour and the difficulty of finding employees restrict the benefit of these arrangements. Yeandle and Stiell (2007) also draw attention to the lack of effective arrangements to protect and support individual care workers, especially those who are directly employed as the personal employees of people in whose private homes they carry out their work. Concerns about job insecurity of those people who are caring for the persons with disabilities, health and safety and the emotionally demanding nature of work in this field are also highlighted in the context of UK.

2.3.2 Ireland

Ireland has comparatively under-developed and poorly co-ordinated community-care services. The Irish welfare state has neo-liberal features, as it is a low-spender on social policies, it relies on the family in care provision, and it is reluctant to assume a substantial role in the direct provision of social care services to older people and persons with disabilities (Timonen, Convery & Cahill, 2006)

Before the introduction of the Home-Care Grants (HCG) in 2001, persons with disabilities had a statutory entitlement to apply for a public subvention that offset nursing-home fees, but there was no equivalent right for community-care charges. As a result of the funding bias, many older people with low and medium levels of dependency are in institutional care (O'Shea 2002: 65, 81).

HCGs can therefore be seen first and foremost as an attempt to counter the institutional bias against older people that is built into the Irish care system and as a measure to stem the spiralling public expenditure on nursing-home care. The perception that it would be cheaper than institutional care was a critical factor in gaining the support of the government (Department of Social and Family Affairs 2002). Economic considerations were therefore the main factor driving the new initiative. HCGs also give greater choice in long-term care to older people and their carers, but while they arguably enable older people to live at home, the grants do not mean a complete break with the traditional care model because their success depends on the significant inputs from informal carers.

A review of current grants has established that most covered only a small part of the costs of the needed care and that three-quarters of HCG recipients had to draw on private funds or informal care (or both), which means that the grant would be unworkable without informal carers and private expenditure (Timonen 2004). In terms of service structure, the care needs of applicants are assessed by public-health nurses or medical social workers, who act as gatekeepers to the system in that they identify the older people most in need of the grants. Therefore, the grant is designed to supplement, rather than replace, the formal and informal services that are in place, but in many cases, the formal provision is inadequate and the grant becomes the only route to significant provision of in-home care (Timonen, Convery & Cahill, 2006). Also, the problem is that although HCGs are the secondary options to community-care services, the lack of these services has made the HCGs the only option. In the absence of any other investment in public home-care services, the expansion is a shift towards private-sector provision.

2.3.3 Germany

Long-term care insurance benefits for both elders and persons with disabilities are divided into four categories: home care (cash benefits), home care (in-kind), day and night care (in-kind) and nursing home care (in-kind). This broad range of benefits has been adopted to offer freedom of choice to care users such as those in the UK (Schneider & Reyes, 2007).

With the cash-for-care provision, home care has been assumed to be the care arrangement most preferred by care recipients and their families, as well as the lowest cost policy option for care provision. The evidence also shows that the highest take-up is for the cash benefit (49 per cent in 2003) in Germany, while the institutional care beneficiaries corresponded to 27.3 per cent and separately and institutional care for disabled people corresponded to only 3.2 per cent in that year (Schneider & Reyes, 2008). Scholars claim that the choices in the long-term care benefits made have important effects on employment in the care sector. As the policy enables care-receivers to receive cash benefits which can be passed to family carers, the policy has significant gendered implications, as women in traditional housekeeping and caring roles in Germany have been affected negatively in terms of employment and have become more dependent within the private sphere while caring for their children with disabilities.

2.4 Outcomes of the cash-for-care schemes: Positive, negative or both?

Almost all studies report that cash-for-care schemes bring positive outcomes to those who use them. In line with the ethos of the residual emphasis on the rights of persons with disabilities that are equal to others, an important goal of many such schemes is

to increase recipients' ability to make choices. As Rummery also indicates, the advantage of cash-for-care schemes over the alternatives, such as formal state social care provision or informal family provision of care and support, is that giving choice and control to disabled people enables them to purchase care and support that fits in with both statutory and informal networks and enables them to carry out their own caring and other duties (Rummery, 2006). As the policy has been giving "greater choice" to its users and as service users have gained the opportunity to combine different types of support such as health and social care (Rummery, 2010), the policy has been welcomed as a victory for the disability rights movement, (Rummery, 2006). Also, it is undeniable that cash-for-care has led elders and persons with disabilities to greater social participation and independence without the 'burden of gratitude' experienced by people receiving informal care from family members or voluntary or paid workers not directly employed by the disabled or older person themselves (Galvin, 2004).

The research evidence suggests that cash-for-care schemes are highly successful, especially in the UK. A study on the carers of disabled children receiving direct payments in the UK proves that the outcomes of the cash-for-care scheme in the UK for the disabled children who are receiving cash benefits has positive impacts on family life, flexibility and close relatives and friends. The evidence from the study suggests that the ability 'to do our own thing' is an advantage that direct payment recipients value greatly, and there is a clear pattern: the vast majority of adults receiving direct payments find the experience extremely positive and empowering, specifically in relation to facilitating increased control and flexibility over the support they receive (Blyth and Gardner, 2007).

The majority of respondents in studies on cash-for-care schemes report a

greater sense of choice and control over their day-to-day lives. There is also much evidence highlighting the psychological benefits to recipients of exercising choice through cash-for-care schemes. These can include feeling more confident, optimistic and positive, as well as increased levels of independence and being motivated to explore new openings or opportunities in ways that might not have seemed possible before (Ungerson, 2004; Yoshida, 2004; Breda, 2006). A common benefit evidenced in cash-for-care schemes in different countries is that individuals can arrange the assistance they buy to fit their particular needs and circumstances. Hence, users can decide, for example, the timing of the institutional visits, the type of support they require, and how it should be delivered (Benjamin, Mattias, & Franke, 2000; Clark, Hough & Macfarlane, 2004). However, it should not be perceived that cash-for-care schemes have no negative impact on care-receiver or caregiver. These policy implementations have been criticized for its negative impact on gender relations and its disregard of the perspective of carers.

2.5 Cash-for-care schemes targeting persons with disabilities and their impacts on care arrangements within households

There are moves across many countries away from state-led provision of services for disabled people towards cash-based systems, which have been welcomed by disability rights groups as increasing choice and control over services and support and increasing independence and social participation. However, feminist scholars suggested that these schemes lead to commodification of social care. In fact, the possible consequences of substituting cash for services for social citizenship have remained largely underexplored. Yeandle and Ungerson (2007) come up with the concept of “commodification of care”, and they emphasize it as follows:

Informal care was becoming commodified through new policies, which involved distributing cash allowances to those living independently, but assessed as needing social care, enabling them to pay their care givers to provide them with services. This form of commodification was deemed especially important both because of its potential for “empowering” care users (in theory, giving them cash rather than services allows care users to decide the nature of the services they receive and to determine who should provide them), and because of its implications for those who provide the services and who are directly “paid” by care users for the work they do. (pp. 2)

Therefore, as I argued before, cash-for care schemes, or “direct payments” in the UK are essentially mechanisms through which a disabled or older person receives a cash benefit in order to purchase help or services themselves in lieu of receiving services or support directly. Although the literature reports positive impacts of cash benefits on the wellbeing of children with disabilities, the dimension of the “caregiver” is generally understudied. The majority of the cash recipients have indicated that parents were concerned about trusting unknown carers and welcomed the opportunity to pay relatives or friends. These findings are consistent with those of Stainton and Boyce (2004), who also found that having friends and relatives as carers makes recipients feel more comfortable and that relationships become more enduring when payment is provided and both parties have clear expectations.

At this stage, it would be significant to discuss the concept of care arrangement in order to understand the gendered impacts of the cash-for-care schemes better. According to Pfau-Effinger, “care arrangement comprises the underlying cultural, institutional and socio-structural framework of a society, on which the concrete structuring of social care and the welfare provision mix is based in each country case and which may change” (Geissler and Pfau-Effinger, 2005, pg. 14). Care arrangements in different countries are particularly important along with the welfare state policies, in explaining the differences between care-related regimes, including cash-for care (Pfau-Effinger, 2005). Care arrangement is based on the idea

that “besides institutional, social and socioeconomic factors, values and cultural models (Leitbilder) regarding the role of different spheres of society for the provision of care also contribute to explaining the way in which care policies and their transformation into social practices develop” (Geissler and Pfau-Effinger, 2005, pg. 22; Pfau-Effinger, 2004, 2005b).

To understand care arrangements in a given context, the relationship between welfare mix and care and the relationship between informal and formal care are analyzed together with reference to the family, the market and labour market structures. Another benefit of using the term “care arrangement” is that it suggests these institutions are embedded into social structures in terms of social inequality through class, gender, ethnicity and the type of income.

Pfau-Effinger divides the types of care arrangements into two: “family values” and “welfare values” based on their “value approach”. The first one is family values, which are based on cultural values as they relate to the structure of the family and the gender division of labour (Pfau-Effinger, 2005a). In addition to the institutional setting of the welfare state, cultural values are the dominant factors in forming models in those kinds of societies. Within such family models, values that are based on “good” childhood are combined with values related to the adequate division of labour within the family. Therefore, it is possible to observe how this type of care arrangement values families in providing care. On the contrary, welfare values “include values relating to the institutions that should be responsible should care be provided outside the family, whether social rights relating to care should be family-based or individual, and the re-distributive role of the welfare state” (Pfau-Effinger, 2005a, p. 25). This type of care arrangement can be best interpreted through Esping-Andersen’s welfare typology and its consequences in terms of care

provision of the state, social rights and the market which he has not taken into account: liberal welfare regime, conservative welfare regime and social democratic welfare regime.

What we understand from the main goal of the cash-for-care schemes is the “empowerment” of the persons with disabilities in terms of greater scale of choice and independency. The word “empowerment” has come to serve as a shorthand term for the idea that consumers of services should be able to determine, far more than in the past, the nature, frequency and timing of the services they receive. However, what feminist scholars and Rummery suggest is that the “empowerment” statuses of the primary caregivers and the gendered implications of the cash-for-care schemes within the household are missing in this debate. It is clear that several normative cores or themes emerge, but none of them appears to be about addressing gender inequalities within the cash-for-care schemes in market economies. As discussed before, some of the consequences of such policies have been reinforcing gender inequalities.

On the one hand, cash-for-care appears in some cases to be attempting to address neo-liberal concerns by reducing the role of the state in providing formal support (often accompanied by concerns about suppressing costs, particularly in cases where the policy is explicitly designed to support moves away from costly residential support, such as in the UK and the Netherlands). Certainly, the feminist approach would point out that when the state aims to reduce its role, it usually expects the family to step in (Stetson and Mazur, 1995) and that this will overwhelmingly mean reinforcing gender inequalities through a reliance on family care. On the other hand, Donnellan (2001) claims that cash-for-care schemes can also be shown to be responding to demands from users for more responsive care and

support and more control over that care and support, as Rummery (2010) argues.

When cash-for-care programmes are designed to formalize and protect the status of employed carers, this is likely to have the effect of “polarizing” the care market (Ungerson and Yeandle, 2007). According to Rummery (2010), this can be emerged through routing payments to recognized care agencies, such as in France and the Netherlands, or through governance mechanisms designed to scrutinize the level and quality of the care received, such as in the UK and the USA (Rummery, 2010). This polarization of the care market is therefore likely to lead to greater gender inequalities within the private, informal, unregulated sphere of care provision.

The other political argument that has had a significant gendered dimension in cash-for-care scheme development has been around campaigns to recognize and recompense women’s informal care work as part of a citizenship agenda (Lister 2002). In the cases where cash-for-care is about replacing, or commodifying, informal care (such as Italy and Austria), it would appear that twin aims can be discerned that do show an awareness of gender-based inequality: first, by freeing up ‘unpaid’ carers to participate in the labour market, and second, by recompensing previously ‘unpaid’ carers for their care work (Rummery, 2010). In the case where cash-for-care development was driven by a desire to protect the employment rights and the status of formal care workers, as in the case of France, given that these are overwhelmingly women, it could also be argued that this was a policy objective intended to address gender inequalities.

Another key debate centres around the impact of cash-for-care schemes on power relationships within households. According to Rummery, first, in low-income families where the use of the cash payment is fairly unregulated (for instance in

Italy), it is likely, based on the distribution and use of money in low-income households, that gender differentials will emerge, with women more likely to use the payments to purchase care and men being more likely to use the payments as part of the general household income (Vogler and Pahl, 1993), leading to a reinforcement of gendered power differences within families. When the cash-for-care policy dominates the policy scene as it does in South-eastern Europe, the cash-for-care may lead to negative outcomes for the female caregivers in terms of their participation in employment. Studies using larger, nationally representative samples have also found evidence of lower labour force participation among parents (overwhelmingly mothers) who care for disabled children. Some scholars find that having a disabled child has a significant negative effect on the labour force participation of married mothers, with the impact concentrated more on low-income families (Breslau, Salkever, & Staruch, 1982). Second, where cash-for-care schemes are used to route money to informal family carers, this can have the effect of creating or reinforcing dependency relationships both inter-generationally (for example, between learning disabled adult children and parent/carers or between daughters/daughters-in-law and parents) and between generations (for example, between spouses) (Rummary, 2010). Finally, the use of unregulated and unsupervised cash-for-care payments, both to pay family carers and directly employ unskilled care workers, has the result of commodifying intimate and sometimes unarticulated relationships and expectations, with the possibility of exploitation and abuse of vulnerable parties on both sides (Ungerson, 2004).

2.6 Conclusion

To sum up, governments have started implementing cash-for-care schemes in line with the strengthening of the social movements of rights of persons with disabilities that put emphasis on empowering them to make their own “choices” independently. However, by doing that, the literature so far indicates that governments are also able to minimize the cost of social care. In the literature, the pros and cons of the cash-for-care payments have been discussed for both the persons with disabilities and the caregivers. What is emphasized is that these cash-for-care policies have different meanings in different social and policy contexts. In the countries where there are no social care policies and informal care work is widespread, these cash-for-care programmes have been perpetuating gender inequality.

When it comes to the Turkish case, the rationale behind the cash-for-care scheme is totally different from that of schemes implemented in other countries. Unlike the examples in European countries, the cash-for-care scheme in Turkey has been implemented in order to support the informal family provision. Although the existing literature has been discussing the social care within the dichotomy of cash-for-care and informal family provision, the Turkish experience indicates that these two may not always be mutually exclusive policy options. While Galvin (2004) suggests that cash-for-care has led persons with disabilities to greater social participation and independence without the ‘burden of gratitude’, the cash-for-care model in Turkey that will be investigated in detail in the following chapters has been fostering the ‘burden of gratitude’. Although there are studies mentioning the psychological benefits to recipients of exercising choice through cash-for-care programmes, this is not the case in Turkey, as the recipients of cash-for-care are caregivers rather than persons with disabilities. The next chapter will focus on the

policy framework for social care towards children with disabilities within the Turkish context in detail.



CHAPTER 3
DISABILITY, SOCIAL CARE AND WELFARE
WITHIN THE TURKISH CONTEXT

3.1 Contemporary social care regime in Turkey's welfare system

In Turkey's welfare regime, the family has a key role in providing social care (Buğra and Keyder, 2006). Since the Justice and Development Party (AKP), which is economically liberal and socially conservative, came to power in 2002, the government has been emphasizing the importance of the family in order to achieve a social solidarity within the domains of social care and social assistance (Buğra, 2002). With the new social policies that have been constituted by a neoliberal approach, they have been playing a significant role in the regeneration of patriarchal values associated with family and women, and the centralization of family within the social care. The AKP's first party programme clearly stated that the power of Turkish families has overcome the financial difficulties with its feature of social solidarity (Buğra, 2012).

The concept of social care in Turkey is usually discussed with respect to childcare policies. Social care for persons with disabilities is understudied in the Turkish literature. In Turkey's welfare regime, as many of the scholars argue, childcare services and pre-school education are not institutionalized (Ecevit, 2015; Toksöz, 2012; Buğra, 2012). The number of institutions and students enrolled in the last decade reveals that both public and private kindergartens and day-care centers have roughly doubled, and the number of students have tripled in the last 10 years. However, the public and private childcare services dichotomy is the most important factor that should be considered. When we look at the total number of private and

public institutions for childcare, the number of total private institutions in 2014-2015 was 3,555 and the total number of public institutions was 2,380 (World Bank, 2015; İlkaracan, Kim and Kaya, 2015). Just by looking at this data, it can be concluded that institutional childcare policies rely more on the market rather than on an inclusive, right-based public policy from which every citizen can benefit. According to Ecevit (2015), there is an ideological reason for the lack of institutionalized childcare in Turkey. Her study shows that the patriarchal mentality in the society and in the bureaucracy resulted in conservative social policies and claims that social services have been reproducing the gender inequalities in the society, largely attributable to the ruling AKP's conservative policies (Ecevit, 2015). As both Ecevit and Akkan have argued, social care has been seen as the role of family within the private sphere in Turkey's welfare regime since Turkey's neoliberal transition (Ekim-Akkan, 2010; Ecevit, 2015).

The lack of universal childcare services and qualified institutional care are determinants of low female employment in Turkey (Buğra and Yakut-Çakar, 2010). This creates a "gendered" and "non-inclusive" citizenship towards women, as most of the childcare depends on home care in Knijn and Kremer's (1997) conceptualization. This division of labour pattern can be observed by using a time use survey in Turkey. According to a time use survey by TURKSTAT carried out between 2006 and 2014, unpaid work comprises more than half of total working time, even for employed women in the labour market (TURKSTAT, 2015). When time spent on household and family care was investigated by sex and employment status, it was seen employed women engaged in household and family care an average of 3 hours 31 minutes per day. The time spent on care was, however, 46 minutes for employed men (TURKSTAT, 2015). Therefore, the survey definitely

shows the underlying reasons behind the low level of labour force participation of women and how women cannot exercise their civil, political and social rights on an equal footing with men in the Turkish context.

It is possible to observe the reflection of party policy in the AKP's public statements. The party politics of the AKP has comprehended the disintegration of the family as one of the most threatening aspect of the modern era (Çitak & Tür, 2008; Ünal & Cindoğdu, 2013). Turkish scholars define the AKP's gender politics as a peculiar form of neoliberal-conservative patriarchy, borrowing from Islamic patriarchy and establishing an intricate alliance between neoliberal and conservative frameworks, which asks women to adapt to global market conditions, yet at the same time expecting them to perform normative wife and motherhood roles (Coşar and Yeğenoğlu, 2011; Ünal & Cindoğdu, 2013). Childcare policies explicitly attempt to strengthen social responsibility among family members, especially the “mother,” within the means of care. The conservative familialism in Turkey gives women a primary role as “mother” to stay at home and emphasizes the caring function of women. Turkey's president, Recep Tayyip Erdoğan has once said “I know there will be some who will be annoyed, but for me a woman is above all a mother” (TIME, 2016) in a speech marking International Women's Day. Similarly, he stated, “Our religion (Islam) has defined a position for women: motherhood” (The Guardian, 2014) where the motherhood gains features of “sacredness” and “blessedness” in this political discourse (Çarkoğlu, Kafesçioğlu & Akdaş-Mitrani, 2012). The statement of Mehmet Müezzinoğlu, who was the health minister of Turkey at the time, stated that mothers should not pursue any professional career but ‘motherhood’. He continued: “Motherhood is the greatest career that women should not give up. It's a career that is unquestionable and sacred” (Hürriyet, 2015). Only by looking at these statements

of politicians it can be claimed that the government explicitly perceives “motherhood” as the centre of acceptable womanhood in contemporary Turkey. Like its childcare and elderly care policies, the government’s main policy towards persons with disabilities is based on financial support provided to the disabled person’s family and the reduction of the institutional care capacity (Yazıcı, 2008). Even Yılmaz and Yentürk (2017) claim that the trends in public expenditures have explicitly demonstrated that the main policy towards persons with disabilities has been carried out primarily through social assistance mechanisms. With the new programme “Aileye Dönüş/Return to the Family,” which was carried out between 2005 and 2010 by the Social Services and Child Protection Agency (SHÇEK), the government aimed to foster the idea that a child is best cared for within his/her family and it would be the best way to minimize the childcare costs of the state (Yazıcı, 2012). In this way, the government aimed to maintain social care for all children, disabled and elders within the private sphere in order to ideologically dignify the role of family as the foundation of society (Kılıç, 2010; Acar & Altunok, 2015).

3.2 Turkey’s experience with disabled care: Institutional care vs home care

In Turkey, both the institutional care and at-home care have been carried out by the Directorate General of Services for Persons with Disabilities and the Elderly under the Ministry of Family and Social Policy. The Provincial Directorate of Family and Social Policies and the Social Care Centres, which were founded in 2013, decide upon the appropriate type of social care models for persons with disabilities, in line with their demands. Although the provision of institutional care for persons with disabilities remained quite limited in Turkey’s welfare regime (Yılmaz, 2011)

compared to the at-home allowance, the provision of institutional care will be discussed first in this chapter before moving to the principal care policy towards persons with disabilities: cash-for-care.

Institutional care provision for disabled people is divided into two: public sector care centres and private social care centres. If a person with disabilities wants to be placed in an official social care centre, first, the person has to be required as handicapped in need of nursing and caring according to the medical report. However, the regulation imposes some restrictions for a person with disabilities when he/she wants to be placed in a private social care centre. In order to benefit from private care centres, the person should first provide a medical report indicating that his/her impairment level is over 70 per cent. In Turkey, as 70 per cent impairment level is the threshold for being registered as a disabled person in need of care, people with 70 per cent and less impairment level are not eligible for either private social care centres or cash-for-care under at-home allowances. Levels of disability has been estimated with the measurement of disability by the Law on Disabled People in 2006 that amended the previous version (Yılmaz, 2011). The new measurement relies on the functionality paradigm that emphasizes working abilities (Evren, 2012). According to the functionality paradigm that is comprised by the abovementioned three categories which are functional citizens, dys-functional citizens who are economically utilizable and dys-functional citizens who are economically non-utilizable; the cash-for-care beneficiaries belong to the third segment of the population, which are framed as disabled persons “in need of care”. Second, social care support is provided to those living under the official income poverty threshold. This means that, in order to benefit from this support, average income per capita must be lower than two-thirds of the minimum wage monthly. The cost of care

services provided for persons with disabilities in private social care centres is reimbursed monthly by the Provincial Directorate of Family and Social Policies. In other words, public financing is used to reimburse care services from the private sector. People who do not meet eligibility criteria can also use these services if they pay them out-of-pocket.

Table 3 shows the comparison between public and private centres for care and rehabilitation in Turkey between 2002 and 2016 in terms of their capacity, the number of beneficiaries and spending allowances.



Table 3. Public and Private Centres for Care and Rehabilitation in Turkey (2002-2016)

	Public Centres for Care and Rehabilitation							Private Centres for Care and Rehabilitation				
	Number of institutions				Capacity		Expenses	Number of institutions	Capacity		Expenses	
	Centres for Care and Rehabilitation (overnight)	Umutevi/Hopehouses (overnight)	Day-care	Total	Number of disabled people in centres (total)	Capacities of the centres (total)	Allowance spending (million liras)	Total	Number of disabled people in centres (total)	Capacities of the centres (total)	Allowance spending (million liras)	
2016	93	128	6	227	7,507	7,458	491	161	11,923	14,236	256	
2015	87	111	5	203	6,926	6,992	353	156	10,823	13,656	222	
2014	85	84	5	174	6,284	6,682	292	149	10,319	13,443	202	
2013	81	48	6	135	5,892	6,293	247	147	10,173	13,325	186	
2012	80	17	7	104	5,586	6,055	218	148	9,328	12,869	137	
2011	77	7	7	91	5,162	5,833	201	100	6,707	8651	84	
2010	69	3	7	79	4,905	5,468	168	77	4,331	7065	45	
2009	61	1	10	72	4,569	4,758	150	44	2,144	3744	17	
2008	56	1	15	72	4,272	4,098	123	20	768	2003	5	
2007	47	0	17	64	4,092	3,434	96	10	351	915	1	
2006	41	0	25	66	4,654	3,027	65	0	0	0	0	
2005	35	0	33	68	4,945	2,755	44	0	0	0	0	
2004	32	0	29	61	4,419	2,415	34	0	0	0	0	
2003	22	0	26	48	4,930	2,086	25	0	0	0	0	
2002	21	0	26	47	3,908	1,943	13	0	0	0	0	

Source: Republic of Turkey. Directorate General of Services for Persons with Disabilities and the Elderly, July, 2017.

It is obvious that the private sector-led provision was stimulated in the area of institutional social care throughout the AKP era. In Altuntaş and Atasü-Topçuoğlu's (2016) field study, they indicate that the emergence of private centres for care and rehabilitation is directly related to the insufficient care facilities in public institutions. Although the numbers of public and private institutions for both care and rehabilitation have increased since 2002, private social care and rehabilitation centres were encouraged to open in 2007 and reached the number of 161, whereas the number of public centres for care and rehabilitation only reached 93 in 2016. In addition, while the capacity of private centres is twice that of the public centres, the number of beneficiaries of private centres are more the number of beneficiaries of the public centres. Although the majority of persons with disabilities are accommodated in private centres for care and rehabilitation, the spending allowance for these institutions is lower than the spending for public centres. The main reason is the difference between public and private centres budgets. This difference also creates a divergence of quality of care services between public and private institutions.

In the same field study, it was revealed that the caring approach of the social workers also differs between the public and private centres for care and rehabilitation. From the discourse of social workers who work in private centres for care and rehabilitation, it can be concluded that they have been calling themselves as an alternative to home-care rather than public care and rehabilitation centres (Altuntaş & Atasü-Topçuoğlu, 2016). Although the private centres are also referred to as "rehabilitation centres" according to the regulation, social workers in these centres are denied rehabilitation services in their institutions. Therefore, theoretically, while the government has categorized the institutional care for persons

with disabilities under public and private but equal in terms of their services, this is not the case in practice.

Persons with disabilities have been largely ignored in Turkey's welfare regime for many years. Although the disability allowance introduced in 1976 emerged as the first comprehensive social assistance policy of Turkey's welfare regime, the policy had a "symbolic" impact on persons with disabilities, as the allowance was restricted to disabled people who lacked a close relative to look after them and whose income was below a specified level (Yılmaz, 2011). It would be meaningful to claim that the policies towards persons with disabilities have been developed during the AKP era, as Yılmaz (2011) also argues. However, the progress in this policy area remained limited to cash-for-care and social assistance programmes (Yılmaz and Yentürk, 2017). Because of income criteria, the disability allowances can only provide cash benefits for persons with disabilities; they do not provide social care. Combined with a lack of capacity and good quality in institutional care centres and a lack of home-based social care services by professionals, social care provision for persons with disabilities has not yet taken the form of rights-based professional services.

3.3 Cash-for-care scheme: A brief overview of the implementation of the prior policy

The 2006 Law on Disabled People introduced an at-home care allowance in Turkey, which is a cash-for-care scheme. The Law explicitly indicates that at-home care allowance should be implemented as the main policy in social care provision for persons with disabilities. This policy assumes that persons with disabilities should be cared within their families and relatives and without being separated from them (Republic of Turkey Ministry of Family and Social Policies, 2006). This policy

choice made cash-for-care scheme the largest item in the public expenditures for disabilities (Yılmaz and Yentürk, 2012; Yılmaz and Yentürk, 2017). At the time of the study, the amount of the cash-for-care scheme was 847,16 Turkish liras (app. 167 Euros). Table 4 shows the number of cash-for-care beneficiaries and the amount of cash allowance in Turkey between 2007 and 2016.

Table 4. The Number of Cash-for-care Beneficiaries and the Amount of Cash Allowance in Turkey (2007-2016)

Years	Number of beneficiaries	Total amount of allowance (million liras)
2016	481,141	5,198
2015	508,481	4,470
2014	450,031	4,056
2013	427,434	3,544
2012	398,335	2,944
2011	347,756	2,214
2010	284,595	1,580
2009	210,320	964
2008	120,000	417
2007	30,638	35

Source: Republic of Turkey. Directorate General of Services for Persons with Disabilities and the Elderly, July 2017.

As it can be seen from the Table 4, the number of cash-for-care beneficiaries increased between 2007 and 2016. While the number of beneficiaries was 30,638 in 2007, it reached 481,141 beneficiaries in 2016. The total allowance amount shows a trend similar to the number of cash-for-care beneficiaries. While the total allowance amount was 35 million liras in 2007, it increased to 5,198 million liras by 2016, which means that the budget also increased. What we understood from this data is that the cash-for-care programme has become the major policy for persons with disabilities within the public expenditures.

In order to be eligible for the cash-for-care, first, a family member of the disabled person who becomes the primary carer should apply to the Provincial

Directorate of Family and Social Policies. The beneficiary candidate has to meet the same conditions in order to receive the cash-for-care. First, the impairment level of the person with disabilities has to be over 70, which would indicate that the person is in need of care. Second, monthly income per capita within the household of the disabled person must be lower than two-thirds of the minimum wage. Between the dates of 01.01.2017 and 31.12.2017, this income limit was 847,16 Turkish Liras. In other words, if a disabled person wanted to receive cash-for-care, the income per capita within the household must be under 847,16 liras in 2017. If the Ministry officials realize that beneficiary's income per capita within the household exceeds this threshold after she was granted the allowance, the cash allowance is withdrawn.

This policy falls short of providing universal coverage for all in need of care due to its targeted character. As the cash-for-care policy excludes persons with disabilities whose income per capita within the household is below the poverty threshold, the state ignores the right of persons with disabilities to be cared for if they are ineligible for the cash-for-care policy. Moreover, the concept of social care has not been acknowledged as a public service. On the contrary, social care has been defined as a family service which is supported by cash-transfers only for persons with disabilities who are "in need" as defined by the regulation (Özateş, 2015, pg. 78).

Unlike the majority of European welfare states, cash-for-care in Turkey has been given to the caregiver –who is generally a relative of the disabled person rather than the disabled person himself/herself. The term "relative" has been defined to include family members according to the 2006 Law on Disabled People (Republic of Turkey Ministry of Family and Social Policies, 2006). What is quite interesting is that the duties and responsibilities that were attributed to family members are more

detailed and heavier in terms of workload than those of nursing staff employed in public and private centres for care and rehabilitation. With reference to the time use and division of labour within the household which I explained in the beginning of this chapter, it can be claimed that the duties and responsibilities of the primary carers of persons with disabilities that have been stated in the regulation have explicitly targeted women, and mothers in particular, within the household (Özer, 2016). Therefore, this requirement illustrates that social care has been totally left to the family and the private sphere, and the state does not assume any responsibility for caring for persons with disabilities. Also, the regulation requires the cash-for-care beneficiary to live with the disabled person in the same house, and it requires that the relative should be responsible for caring for the disabled person round the clock. Employment rights of caregivers are not recognized.

However, in some cases, the regulation accepts the condition that the relative could reside in a different address than the disabled person's one. When this is the case, the regulation imposes an obligation for the relative to be together with his/her disabled relative who is in need. Yet under all conditions, the necessity of meeting the needs of persons with disabilities by only their family members has formed the basis of the cash-for-care policy. Therefore, the conditions of at-home care allowance in Turkey are much heavier than in European welfare states, as the policy gives no leave option for family members to go out, socialize and be a member of the society except for providing care for their disabled relatives (Özateş, 2015, s.79).

Toksöz (2011) claims that the fact that people who are responsible for caring their relatives with disabilities within the household are mostly women is a socio-economic reflection of the gendered division of labour in Turkey. This issue will be discussed in the next chapter in more detail.

3.4 Cash for disabled care and its impacts on care arrangements within family in terms of gender relations, commodified work and domestic network

When we compare the number of beneficiaries of cash-for-care with the number of persons with disabilities who have been receiving social care in public and private centres, it can be definitely claimed that the vast majority of persons with disabilities receiving public support are cared at home. By looking at the social care regime in Turkey, it is not incorrect to claim that the care burden has been laid predominantly on women. Besides the pattern of time use of both men and women in the household, women's labour force participation rates also show that the share of women has constituted the vast majority of the private sphere in Turkey's welfare regime. Therefore, it can be claimed that the implementation of the cash-for-care policy in Turkey is mostly carried out by women so that the state can minimize the costs of social care and social workers, as the care work is carried out within the private sphere instead of public. As a result, the cash-for-care policy reinforces the traditional and patriarchal roles of women, as they are obliged to carry out the social care work for their disabled relative within the household (Altuntaş & Atasü-Topçuoğlu, 2014). Özer (2016) suggests that the regulation on the conditionalities of at-home care allowance is a form of "formal" exploitation of women's labour.

In Turkey's welfare regime, although cash-for-care is given to the relative of the disabled person rather than the disabled person himself/herself, the main aim of the providing cash transfers is to address the needs of the disabled person, which means that the cash-for-care is not given for the women's care work at home. Also, it is also important to discuss patterns of responsibility for cash-for-care and control over household financial management. According to the regulation, the spending of

cash-for-care beneficiaries is not limited to the needs of their relative with disabilities. This means that, while the cash-for-care beneficiaries are “advised” and “obliged” to spend their at-home care allowance for the needs of their relatives with disabilities, they are also free to make this spending on the household expenses, as there is no inspection on how the cash-for-care has been used. Therefore, as in the fact that there are no criteria for the spending of cash-for-care, there is no regulation on caregivers that would check whether the home-care has been carried out sufficiently. As the at-home care allowance is a cash benefit, it could be claimed that the policy does not provide any qualified care. In this way, the policy lacks the ability to provide high-quality care services.

When we compare the implementation of cash-for-care in European welfare regimes and Turkey, the policy in Turkey goes far beyond removing gendered implications of at-home care allowances. On the contrary, it would be obvious to claim that the gendered implications of both social care and cash-for-care policy are intertwined with each other in the Turkish welfare regime, as both of them have been regenerating the traditional gender roles of women.

As Tronto (2006) has claimed, the unequal citizens—predominantly women—who have provided care only in the private sphere are becoming more exclusive rather than inclusive citizens, which deepens the inequalities. This situation comes to the reality as well, even in the implementation of the cash-for-care policy in the Turkish context. When the care work of disabled person in need of caring and nursing has been carried out in the private sphere, the women’s inequality in the public and private sphere continues to be fostered by state policies.

CHAPTER 4

AN EXAMINATION OF THE CASH-FOR-CARE POLICY IN THE ATASEHIR AND SULTANGAZI DISTRICTS

The 16 caregivers involved in this study have been living in Istanbul's Ataşehir and Sultangazi districts. Half of them were still receiving cash-for-care, while the cash allowance has been cut off for the other half. A vast majority of the women are married, and only three of them are divorced. Also, while only two carers had informally worked as cleaning ladies part-time, the rest were housewives when I asked about their employment status. While two carers reported that they were involved in paid employment before they started to receive a cash allowance, the rest stated that they had not been in either paid or unpaid employment before. The number of the people living in the same household ranged from two to eleven. Although I did not want to limit myself to conducting interviews only with mothers of the children with disabilities when I first designed this research, I could not find the fathers of these children when I visited these houses. This phenomenon proves that the cash-for-care scheme relies heavily on women's unpaid domestic labour. In this chapter, the interviews with these women have been analysed under five themes: application to the scheme, attitudes towards cash scheme, impact of cash scheme, care arrangement and spending arrangement.

4.1 Application

In terms of application, I asked about the caregivers' experiences in their admission process for the cash-for-care programme. First of all, my informants differed in terms

of the time of their first application and admission to the scheme. Among eight carers, one had been receiving cash allowance for 10 years, the longest time, whereas the shortest time was only a year.

Among the carers who were currently receiving cash-for-care, very few caregivers reported that they had found out the existing policy themselves. This means that the vast majority of the carers had learned about the cash-for-care policy by following different paths. When we look at these paths, I found that some of the carers in Sultangazi had learned about the policy “accidentally”. Of these caregivers, few of them heard about the policy by chance from their neighbours, and the other said that they had accidentally learned about this cash allowance scheme from one of their friends.

Well.. We heard about this cash-for-care policy from one of our neighbours in this neighbourhood. Our neighbour has a disabled child too, so they told us. I hadn't heard about such policy before.
(Ayten, 45, Sultangazi, still receiving cash-for-care)

Actually, nobody told us anything about this cash allowance. We heard about this policy from our neighbour, by chance.
(Arzu, 35, Sultangazi, still receiving cash-for-care)

One of our friends told us about this social assistance. I mean, we heard about it by coincidence. We were a bit late.
(Songül, 52, Sultangazi, still receiving cash-for-care)

However, in Ataşehir, half of the carers who had been receiving cash-for-care reported that they had heard of the policy by doing their own online research on cash schemes. They also criticized the officials of the Ministry of Family and Social Policy for not distributing information widely on this cash allowance scheme, especially among the parents of children with disabilities. These carers also reported that, although they went to the doctor to get a health report (medical disability report)

for their children, none of the doctors informed them about their eligibility to benefit from this cash allowance.

First, I went to the Provincial Directorate of the Social Work. I stated that my son has a few disabilities. I learned that I have such rights after doing some research. I mean, no one helped me or gave advice. I learned these rights by myself. Then I went to the doctor with my son in order to take a disability report for him. The doctor said nothing about the existence of such policy. Luckily, I made this research before visiting the hospital so I am aware of my rights.

(Meryem, 35, Atasehir, still receiving cash-for-care)

Sena is also one of the cash beneficiaries who learn about the at-home cash allowance by herself:

I made this application by myself, I mean, I did not receive any support from an institution. After doing some research, I learned that the government is not giving any social assistance to the family until their child is 2 years old because they have been considering that the mother should be responsible for caring their children in first two years. So, we had to wait to apply for this cash. However, when we went to the doctor, the doctor said nothing about this policy...

(Sena, 32, Atasehir, still receiving cash-for-care)

In Atasehir, the other carers reported on how they had heard about this cash-for-care policy differently. While one of them reported that they had heard it from the public hospital such as the one of the carer in Sultangazi, the other carer was the only one who reported that she had learned about this cash-for-care policy via a rehabilitation centre.

We did not make this application by ourselves. There was a rehabilitation centre in our neighbourhood. They recommended we apply for it. They told me 'ma'am, you are eligible for it, you can receive this assistance'. So, they described the institutions that we should deal with and we went for it.

(Ayşe, 38, Atasehir, still receiving cash-for-care)

When we look at the role of the social workers in the carers' application process, normally, we should expect some home visits of social workers to those families who applied for the cash-for-care. However, half of the caregivers who had been

receiving cash-for-care said that no one from the Ministry of Family and Social Policy visited their homes when they applied for the cash-for-care. This situation demonstrates the lack of standardization in the application process in terms of legality and in practice:

Yes, someone came from the ministry. At that time, we weren't in this house, we were living in the previous one but they did not enter the house. They just asked some questions while standing at the door. I mean, they did not step inside our living room or other rooms. They did not come to this house either. (Sena, 32, Atasehir, still receiving cash-for-care)

Arzu also mentioned that they had not been visited by social workers, which is contrary to the regulation:

No, nobody visited our home from the ministry. We gave the disability report for our child, and then our income status, and we noticed that we have started to receive our money. (Arzu, 35, Sultangazi, still receiving cash-for-care)

While these carers started to receive their cash-for-care without any home visits from the ministry officers, what we understood from the rest of the carers' statements is that the officers from the ministry visited the vast majority of the households and spent much time for making observations on both the status of the children with disabilities and the houses. Half of the carers who had been receiving cash-for-care indicated that they had been visited by the social workers and officers from the ministry more than once at long intervals. One of the carers who had been receiving cash-for-care for seven years stated that they had been visited by a ministry officer last year for the first time in these seven years.

Yes, they came to our home for the first time last year, nobody came before. They asked some questions like 'who is working', I said, 'only my husband is working'. They also asked whether my daughter was working or not, I said no. They asked too many questions to us. They just looked at my son, they did not ask any questions to him. They also looked at our furniture, other objects in the living room and they left. (Songül, 52, Sultangazi, still receiving cash-for-care)

Yes, they came like four years ago but they also visited our home when we first applied for the cash. They talked to us, they talked to Cemile, they observed our behavior towards her. They also asked her some questions about her body language. And they left the house after writing a report about the visit.

(Hacer, 43, Sultangazi, still receiving cash-for-care)

Discrimination against caregivers and their children with disabilities in the application process have emerged from the field work as well. What is striking is that caregivers have been discriminated against because of their disabled children and have been exposed to misbehaviour from government officials while they were applying for cash-for-care. A large number of respondents expressed their disappointment while they were telling their stories:

When I first applied for this cash-for-care, I went to the district governor. The lady asked me whether I would like to have 'beggary cash'. I was shocked and said 'no, I am not begging. I want to apply for the cash-for-care for my disabled child. I am not here to beg for money from you, I am here because this is my right'. The officer's attitude was disgusting.

(Meryem, 35, Atasehir, still receiving cash-for-care)

Sena also shared an experience on the perceived discrimination against herself witnessed by one of her friends while she was making an application for the cash-for-care:

One of my friends, who also has a disabled child, made an application for cash-for-care like a year ago when I first applied. She told me that an employee from the Social Services unit in Uskudar scolded her very angrily. She said the attitude of that woman from the institution was like she was someone who is giving her dad's money... My friend was denigrated unjustly. It was really rude. I saw the same woman when I was applying for the allowance and again, she treated me as a beggar.

(Sena, 32, Atasehir, still receiving cash-for-care)

4.2 Attitude towards the cash scheme

In terms of the cash beneficiaries' attitudes towards the cash scheme, I asked their opinions about the amount of cash-for-care and whether the needs of their children with disabilities had been met by this additional income.

Caregivers' attitudes towards cash scheme are diverse especially with respect to its amount and its program design. Although there are many respondents who found the amount of cash-for-care "necessary" and "sufficient" in order to meet their needs, there are many respondents who criticized the amount of cash-for-care for being very "low" and "insufficient".

Among 16 caregivers who were still receiving cash-for-care and the ones whose cash benefits had been cut off, half of the caregivers reported that they found the amount of cash benefit very suitable, and they were happy with it. Although some of the respondents have also indicated that the amount of this cash allowance is sometimes insufficient to meet the needs of both the disabled child and living expenses within the households, they all indicated that they were pleased with the amount of care allowance. While they were giving their opinions about the amount of the cash-for-care, all of them used religious references (i.e. "may God bless the ones who are giving this money"). This framing was more common in Sultangazi than in Atasehir:

The amount of this cash depends on the state. Everyone demands more. Everyone will say okay if the wages get higher. Could we say no to higher wages? If the wages increase for elders or persons with disabilities, can we say 'no'? I think the amount of this money is insufficient but anyway, may God bless our government, our state.
(Fatma, 40, Atasehir, still receiving cash-for-care)

Unlike Fatma, Arzu and Ayşe expressed that they found the amount of cash allowance insufficient but still, she praised the government:

Well, of course the amount of this cash is unsatisfying but still, we are grateful for what we have. May God bless our government for this money. We are thanking God every morning when we wake up for being alive. (Arzu, 35, Sultangazi, still receiving cash-for-care)

Of course, I would like to receive more but still, we are thanking our government for what they were giving. Thank God for today. We are not demanding more because the state is not our father's son. We are using what they have considered appropriate for us. (Ayşe, 38, Ataşehir, still receiving cash-for-care)

The other half of the respondents of the 16 caregivers reported that the amount of the cash-for-care was insufficient, and a vast majority of them indicated that this policy was “for show only,” not based on a rights-based approach. Unlike the caregivers who had been thanking for God for receiving this assistance, caregivers who were unsatisfied mentioned the unmet needs of their children with disabilities and household itself and gave a different rationale and coherent reasons for why they found this cash inadequate. What is quite interesting is that the ones who were complaining about the amount of the cash were generally the ones who had not been receiving cash-for-care at the time the research was conducted due to changes in eligibility criteria for the cash-for-care scheme:

It is insufficient, very insufficient. As I told you before, we cannot work. I don't know, probably some of them came on your way while doing interview with us (referring to the caregivers). There are many people who are grateful for this money saying ‘Oh God, thank you for it...’. To be honest, I do not appreciate our government for this money. The government provides this money for us to survive. It is not a benefit for our disabled children, it is like a living wage for us and they are providing it to us within this approach. The cost of a basic breakfast a week is approximately 150 Turkish liras. You can calculate the rest of it. This money is my wage to survive. Why am I supposed to praise God for this money? I rebel against it. (Meryem, 35, Atasehir, still receiving cash-for-care)

One of the caregivers who reported that their cash-for-care has been cut off due to a change of address complained both about the amount of it and the reason for the cut-off by, saying:

(Laughing..) Well, I think the government is making fun of us... It is reasonable to cut off the money as a result of change of address without calling us, informing us or inquiring about it? What I understood from this experience is that they hold a grudge against us for this money, I mean, this money is for show only. I am very desperate and offended.
(Hacer, 43, Sultangazi, still receiving cash-for-care)

As an exception, very few caregivers indicated that they had seen the cash-for-care as “alms” because of its amount and they both reported that what the government is giving this money to its citizens looks like “giving to a charity” for its “beggars”.

However, they indicated that they would have faced difficulty managing their expenses if this assistance had been cut off:

Cash-for-care is like... alms! I am not predicating on my myself but I have a very close friend whose husband is currently unemployed. Their oldest daughter is very successful despite of their living conditions. She wants to invest in her daughter more but it is not possible. These four people are only living with this cash-for-care without any additional income. Her mother-in-law is paying their rent. Otherwise, it is impossible. Her disabled child should have a medical operation so she is always rushing to governmental institutions without any support. She told me something recently: Although we have been receiving this money, we are obliged to spend half of it in public transportation because carrying a disabled child is very difficult.
(Sena, 32, Atasehir, still receiving cash-for-care)

While Zuhail was telling her story, she emphasized once again that the cash-for-care had not been designed on a rights-based approach:

I am sure that there are hundreds of people who are pleased with this money but I am not. The rent of this house is 700 Turkish liras. Luckily, my ex-husband is paying half of it. Now, our cash has been cut off. I have been going to my neighbours' houses to clean and I was able to earn only 150 liras in two weeks. How about our food, my son's drugs, hygiene, clothing? Since this money has been cut off, I could not buy anything additional besides our basic needs. What I understood is that, yes, because of this cash, we were able to breathe easier but still, I am sorry for them as they were giving this money as alms rather than a “social right”. Why did you cut my only wage without any warning?
(Zuhail, 51, Sultangazi, cash-for-care has been cut off)

Very few caregivers mentioned that the amount of cash-for-care should be equal to the amount of minimum wage, as they saw themselves as “labourers” caring for their children in the household. This was also very exceptional in the fieldwork:

The amount of cash-for-care should be the same as the minimum wage and the government should offer retirement pensions for the mothers of children with disabilities. I have worked before but my 11-year career will go to waste, all of my insurance premiums... I have paid in premiums to the government funds and I don't know where they went. That money is hurting me. If the state is not retiring us, then I think they have to give my money back as compensation. Either retire me or pay that money back because I have an incredible concern for the future.

(Sena, 32, Atasehir, still receiving cash-for-care)

Actually, we are like household. There is no significant difference between workers and us. On the top of it, for me, what we have been doing is priceless. The amount of this cash should be same as the minimum wage I guess. It is not fair to live in this squalor but we have been living like this. Before Murat (her son) started to work, I remember the days when we ate only bread at dinner.

(Tuba, 40, Sultangazi, cash-for-care has been cut off)

To understand caregivers' attitudes toward the cash scheme in detail, I also asked the respondents whether they would like to have additional support from the government in terms of institutional care, home care service providers such as nurses, careworkers, or related social workers besides cash-for-care. Although the caregivers' opinions about the amount of cash-for-care were quite diverse, I observed a common pattern in the responses to this question. Half of the caregivers reported that they were totally against institutional care for their children with disabilities. Within these respondents, half of them indicated that they were not able to leave their children in a care institution as long as they are alive, and the statements were all the same which is “no one can take care of my child, except me”. It is also interesting that the ones who had been against institutional care include both ones who found the amount of cash-for-care both “sufficient” and “insufficient”:

Who wants to accommodate his or her disabled child from somewhere else? Yes, the government gives such an opportunity but how dare you leave that child to those care homes? My child cannot protect himself; he is dependent on someone else. When someone touches him, he falls down. That's why we did not send him to any kind of school, as he cannot protect himself. As his parents, we are caring for our children with so many difficulties, how do they care for him?

(Songül, 52, Sultangazi, still receiving cash-for-care)

Until now, I have been caring for my disabled child. I have been providing all her needs. I mean I have been facing so many difficulties while caring for her, how can someone else deal with her and care for her as much as I can? Hospitals, care centers... No. If anything happens to us, okay. But if not, I am thankful for what I have.

(Zuhal, 51, Sultangazi, cash-for-care has been cut off)

Caregivers who are against any kind of institutional care but are also unsatisfied for the amount of cash-for-care indicated that they would like to have support from the government in terms of home-care service. The number of caregivers who were demanding nurses and social workers for caring their children is higher among the caregivers whose cash-for-care had been cut off than the caregivers who were still receiving it. However, the number of caregivers who were demanding home-care service was relatively small. Therefore, the result is that caregivers who are satisfied with the amount of cash-for-care do not demand any additional support, but they would like to continue receiving this cash allowance. However, caregivers who are unsatisfied with the amount of cash-for-care would like to have both cash-for-care and home-care services:

You know what? I have never said something like 'God, please take my child... Did I commit a sin?' while caring for my child. I wish I could be alone with myself just for one hour but I know that this could only happen with some nurses, like maybe doctors who are specialized in this field. They can take care of my child at my own house so I can see what he's doing. Otherwise, I cannot leave my child in an institution even if they are specialized on disability. I thought about this issue so many times but no.

(Nurten, 39, Sultangazi, cash-for-care has been cut off)

What I found interesting from the fieldwork is that, one fourth of the caregivers could not even think of any additional support except cash-for-care. Although I tried

to come up with disability benefits without making any kind of guidance, both of them mentioned their mother-in-law as their “substitute” for cash-for-care while caring for their children. These respondents’ statements show how the care work has been considered as gendered domestic work and indicate its impact on the care arrangement:

- Think about a public or private institution who would care for your disabled child... What type of support would you like to receive?
 - + For caring?
 - Yes, caring for him.
 - + I think it would be impossible; we are not doing something like you said.
 - Yes, I know but would you like to have it?
 - + Yes but it won’t be happening I guess. My mother-in-law is also caring for him.
- (Ayşe, 38, Atasehir, still receiving cash-for-care)

I could not think about such support... My mother-in-law is already caring for him when I have to go out. We don’t need that.

(Fatma, 40, Atasehir, still receiving cash-for-care)

One of the carers from Sultangazi, Songul, emphasized that she did not think of any additional support along with cash-for-care until now, because she never witnessed any day-care services or professional carers that are provided by the government in addition to cash allowance:

You know what? I never thought this question before. Actually, I cannot guess any additional services because I never witnessed before. If the government is providing us this cash benefit, then we should say “thank goodness” to them, instead of looking for opportunities.

(Songül, 52, Sultangazi, still receiving cash-for-care)

The market option (buying care services) came to very small numbers of caregivers’ minds when I asked about any other social support that they would like to receive in caring for their children. However, as cash-for-care is an allowance which is provided to the “poorest of the poor”, respondents explained how paying a formal caregiver with a professional background would be unfeasible under the following circumstances. These caregivers did not think about any home-care services such as

professional caregivers and nurses that are funded by the government, which is quite interesting again:

After I gave birth to my daughter with disabilities, I wanted so much to work again. Let's say that I got a job again and started to earn 3,500–4,000 Turkish liras. I have to find a caregiver also for her but this caregiver cannot be a regular person. She has to know how to give medicine, what to do when my daughter suffers an attack... I have to spend like a minimum 2,000 Turkish liras to care for her. If I get a job, my cash-for-care will also be cut off. Then, this means that I have to work for like only 1,000 liras but I won't feel comfortable: Did my daughter swallow the medicine carefully, did the caregiver see her... So many worries. Therefore, I gave up on getting a job but I questioned the situation many times.
(Sena, 32, Atasehir, still receiving cash-for-care)

4.3 Impact of the cash-for-care programme

In terms of the impact of cash-for-care, I would like to figure out how the cash beneficiaries evaluated the policy with respect to their socio-economic conditions.

When I asked respondents about the impact of cash-for-care on their economic situation before and after receiving the allowance, the answers of still receiving cash-for-care and caregivers whose cash-for-care has been cut off were quite different. Among the caregivers who had been receiving cash-for-care, half reported that the cash-for-care had a positive financial impact on their situation. Many of them compared their economic conditions before and after receiving the cash allowance while they were telling their stories:

When we were not receiving the cash allowance, we were 'really' poor... I mean, we are also poor now but things have changed. Before, only one of my sons was working because the others were small. He was earning 600 liras a month. I have nine children and that 600 liras was the only income of this household. No one gave us money or food in those years. We could not eat freshly-baked bread until we started receiving cash-for-care.
(Arzu, 35, Sultangazi, still receiving cash-for-care)

Among these people who have mentioned that the cash-for-care changed their economic condition in a positive way, very few of them indicated how much gratitude they felt to the government when their income increased after receiving cash allowance. However, although they mentioned that the cash-for-care was very beneficial in terms of living expenses for better living standards compared to their situation before receiving it, none of them indicated that the care allowance had a positive impact on the needs of their disabled child in terms of financial management of the cash allowance within the household:

Of course, there is a significant difference between our economic condition before and after receiving cash-for-care. May God bless our government. We can buy food and pay for other household expenses with that money.
(Songül, 52, Sultangazi, still receiving cash-for-care)

Limited number of the respondents reported that cash-for-care did not have a significant impact on their economic well-being in terms of caring for their disabled children. Both of them indicated that the care allowance enabled them to pay their rents effortlessly. Although both of them were aware of the fact that the cash-for-care had to be used for caring for their disabled children, they mentioned that the cash allowance made their household comfortable in terms of paying rents:

Well, nothing has changed much before and after receiving cash-for-care. We are receiving this money in order to take care of my child but we are using that money for our rent. It doesn't work for my child.
(Ayşe, 38, Ataşehir, still receiving cash-for-care)

While Fatma's story was the same as Ayşe's, she also mentioned the other living expenses of their household that were covered by the cash allowance:

This care-allowance has an impact on us, only for paying our rents easier. Also, it becomes a financial support for electricity, etc. When I compare our economic condition before and after receiving this money, I don't see a big difference in terms of caring for my disabled children. Maybe, only for our rent and living expenses.
(Fatma, 40, Ataşehir, still receiving cash-for-care)

When it comes to the caregivers whose cash-for-care had been cut off, the pattern is different. After their cash allowance has been cut off, the economic well-being of the respondents differs in terms of their reason of losing the right of receiving cash. In other words, the reason these caregivers are not eligible anymore for the cash-for-care is a significant factor in answering my question on their economic and social situation after their cash-for-care was cut off. Among the caregivers whose cash allowance had been cut off, the majority of them reported that their economic condition had changed in a negative way when they lost the eligibility for receiving cash allowance:

Of course, the things have changed in a negative way after we learned that we were not eligible for receiving the money anymore. I mean, the amount of this allowance was not too much but still, it helped us. Besides the needs of my disabled child, we have a lot of living expenses. Now, we cannot afford to make extra spending. By saying 'extra', I didn't mean something useless. I mean, maybe an additional piece of clothing that my child liked when we went out for shopping.

(Serra, 59, Sultangazi, cash-for-care has been cut off)

While another caregiver, Zuhail, reported that their economic condition deteriorated after losing the eligibility for cash-for-care, she complained about the fact that they lost the right to receive a cash allowance as their income per capita within the household exceeded the threshold of 847,16 liras by only five liras, which is 852,16 liras in total:

As one of my sons started to work, our income per capita has changed. However, we passed this threshold by 5 or 10 liras. I mean, our income hasn't changed, we are still poor. When they cut this care allowance, our economic well-being got worse.

(Zuhail, 51, Sultangazi, cash-for-care has been cut off)

Among the caregivers whose cash-for-care had been cut off, very few of them indicated that they started to work informally as cleaning ladies in the neighbourhood after their economic situation got worse. Both of them told me that one of their

closest relatives had been taking care of their disabled child when they went to work. Both of them were working as informal, sometimes part-time, due to the condition of their disabled children and the fact that they were uninsured:

When I was married, I was taking care of my disabled son, Mustafa, all day. When we were divorced, I moved to a different house and didn't inform them, so that's why they stopped giving this money to me. I am dealing with the application process again but my economic condition has been hit badly. Now, I am working as a cleaning lady in our neighbourhood in order to pay at least my rent. My mom has been taking care of Mustafa while I am working. (Mine, 35, Ataşehir, cash-for-care has been cut off)

Nurten, the other caregiver who started to work as a cleaning lady after the cash allowance was cut, indicated that cash-for-care was the only income that she earned before the allowance was cut off:

I didn't have any additional income except cash-for-care when I was receiving it. Now, my only income is the money that I have been earning from cleaning. That's why my economic condition got worse when I was stopped receiving the care allowance. My ex mother-in-law has been taking care of my disabled child when I am out for cleaning. (Nurten, 39, Sultangazi, cash-for-care has been cut off)

The rest of the caregivers indicated that nothing changed when they stopped receiving cash-for-care. However, there is a significant point here: These caregivers explained the reason behind their cut off in the cash allowance as an increase in their income within the household. In other words, these caregivers' cash-for-care has been cut off due to an increase in the wages or enrolment in a paid and secured employment of a family member within the household. Therefore, as these caregivers' relatives, especially their daughters and sons, started to work formally at the minimum wage, they lost the right to get social assistance but instead, started to live with a better income. That's why they indicated that there was no significant change in their economic situation before receiving cash-for-care and after it was cut off:

When we were receiving cash-for-care, we had a good, financial support for our household, like 940 liras. At that time, my husband was earning a much smaller wage compared to the care allowance. Now, my husband is working in better conditions, with a better wage, so nothing has changed since we lost the eligibility to receive cash-for-care.

(Hatice, 39, Ataşehir, cash-for-care has been cut off)

However, all these caregivers indicated that if the reason for the withdrawal of the cash allowance was something else other than an increase in the wages or enrolment in formal employment of a family member, their economic condition would be changed in a negative way.

4.4 Care arrangements

As Pfau-Effinger suggests, besides the welfare state policies, cultural values and models are important in understanding the structure of the family and the gender division of labour within the household. Therefore, the term “care arrangement” may be helpful in capturing these cultural and family values within the household in care-related regimes (Pfau-Effinger, 2005). To find a pattern for this, the cash beneficiaries were asked about the role of family members in caring for their disabled child.

The questions revealed similarities and differences between two districts in care arrangements.

First of all, in all 16 households, the primary caregivers were mothers. While all of them mentioned that they were the primary caregivers for their children, a vast majority of them also mentioned their husbands or daughters or sons as secondary caregivers. Within the respondents who indicated that their children were also helping her while caring for her disabled child, many of them reported that their daughters were more involved in caring activities than their sons in the household.

The ones who reported this form of care arrangement are more common in Sultangazi than Atasehir. In Atasehir, the respondents mentioned more frequently their husbands as secondary caregivers:

I am the one who is caring for my child, is there any other way? Sometimes my other daughter is also helping me.
(Songül, 52, Sultangazi, still receiving cash-for-care)

He (referring her husband) is also looking after for our disabled son but he is not able to care for him as much as I do. When he wakes up, he goes outside of the house; he meets with his friends... I am always at home dealing with the children, food, cleaning etc.
(Arzu, 35, Sultangazi, still receiving cash-for-care)

Actually, I am the main person who is caring for our disabled child. I mean, the other family members are also helping me because they are working. They are bringing home the bread, this is also a support I guess.
(Ayten, 45, Sultangazi, still receiving cash-for-care)

When I asked them how they managed care when they had to go to grocery shopping or to neighbours or friends, the most common answer is “by turns”. What I understood from all the caregivers is that they could manage care provision at home in such circumstances by leaving their child with second or third caregivers within the household. However, it should not be understood that securing this arrangement is easy. On the contrary, the caregivers living with fewer than four family members (mother, father, a child, a child with disability) reported that they were facing many difficulties in such circumstances. These caregivers reported that their relatives such as mother, mother-in-law and daughter-in-law were helping them in such cases especially if they were living nearby:

I cannot leave my son at home, with the neighbours or somewhere else because we are alone. I am divorced; I don't have any relatives. If we need to go grocery shopping or something urgent, we go together. You are dependent on him, he is dependent on you. I have only one other child but he says ‘Please keep me out of this, I don't want to deal with your problems.’
(Meryem, 35, Atasehir, still receiving cash-for-care)

In such cases, I leave my son with my daughter-in-law or if my daughter is at home, then she is caring for him. Sometimes I go to the local market here with my disabled son, but sometimes I leave him with my daughter or daughter-in-law. She is living nearby, so if she decided to move elsewhere, I would have difficulties, I am sure.
(Songül, 52, Sultangazi, still receiving cash-for-care)

Therefore, it can be concluded that large families face fewer challenges when they have to manage the household in urgent cases such as grocery shopping.

Actually, we are not facing any difficulties in urgent cases because we are nine people living in the same house. For instance, my smallest daughter and my disabled one were alone at home yesterday. They have so many friends in this neighbourhood and they all love Hasibe (their disabled daughter) so much. My smallest daughter asked one of their friends if they could buy a waffle from the market and they actually bought and brought home one.
(Hacer, 43, Sultangazi, still receiving cash-for-care)

Also, a vast majority of the caregivers who have husbands mentioned that their husbands are responsible for the grocery shopping when they come back from work. What is interesting is that this model does not work in families in terms of their care arrangements when a disabled child lives in the household. I have observed the same pattern in all the households that I talked to except two:

I don't have any neighbours but I have lots of friends. For instance, we will go to one of our friends tonight for dinner so we will take Ayşegül (their disabled child) with us as well. When I have to go to the health care center once in 15 days to get a prescription, my mother-in-law comes and takes care of my daughter. I don't have any grocery shopping that is urgent as we put all our needs in our kitchen for any circumstances but if I need anything specifically, my husband brings it home on his way back from work.
(Sena, 32, Atasehir, still receiving cash-for-care)

When my children are in school, I am mostly with Ayşe (the disabled child) at home. The time flies when I am dealing with food, laundry etc. When my husband and my children come back from work and school, I go out of the house if there is something urgent. Otherwise, my husband is bringing the stuff from the grocery on the way back home.
(Leyla, 48, Atasehir, cash-for-care has been cut off)

These two respondents are all from the cluster of “cash-for-care has been cut off”, which is not a coincidence. They reported that they started to do informal work such as going to clean other houses in order to earn money after their cash-for-care benefit was cut off. However, as these two have been divorced and do not have a relative to take care of their disabled children (except for their mother or another child), they reported that it would be impossible to work in a formal, full-time job as they have to continue caring for their disabled child. Therefore, what they stated is that they have to go to the houses for cleaning together with their child. But they reported that their children have been mostly discriminated by the homeowners:

As a person who is alone with her disabled child, both going for cleaning and caring for my child are very difficult. I went to the houses that I am cleaning a few times with my daughter but the homeowners’ faces were annoyed when they saw my daughter. They avoided her like the plague. It was disgusting. I won’t take her with me anymore. Probably, I am going to leave her my ex-mother-in-law. Therefore, when I need something urgently from the grocery, we buy them on the way back home.

(Nurten, 39, Sultangazi, cash-for-care has been cut off)

Although respondents suggested that relations with neighbours are very strong in these two districts, none of the caregivers reported that their neighbours were an option for leaving their disabled children. None of the caregivers leaned on their neighbours when it came to taking care of their children. The first reason is that the vast majority of the carers reported that their children have felt agitated in all places except their own houses. This means that children with disabilities can feel comfortable only in places that they have known for a long time. Therefore, caregivers prefer not to leave their children with their neighbours when they have to visit a grocery store or health care centre. Second, few caregivers indicated that their neighbours have not been able to care for their child as much as they themselves do. Therefore, they reported that they have been trying to manage the care arrangement

within the household when there is an urgent need, without involving their neighbours:

When I have something to do myself, I leave my child with my other daughter because she is my daughter. Otherwise, I can't leave him with others like neighbours etc... This is something about trust.
(Songül, 52, Sultangazi, still receiving cash-for-care)

Actually, my neighbours are open to caring for my child but my child is very active and runs all the time. He feels like a stranger in the neighbours' house.
(Ayşe, 38, Atasehir, still receiving cash-for-care)

Although few of the caregivers brought up the issue of "trust", Meryem gave her disabled child's conditions as a reason:

Well, my son doesn't listen to me. I mean, he is 17 and he always wants to go. If I would leave him to our neighbours, I am sure that he would lead to disturbance. I am not in favour of leaving my son to neighbours even though I trust them.
(Meryem, 35, Atasehir, still receiving cash-for-care)

4.5 Spending arrangement

In terms of spending arrangements, questions about how the cash-for-care has been spent were asked. When I first asked whether there was a difference between the amount of the cash allowance when they first applied and the amount of the cash allowance that they were currently receiving, I found out that the vast majority of the carers were not aware of the exact amount of the cash they have been receiving:

The amount of the cash-for-care has changed in these 3 years. It was like 740 Turkish Liras 3 years ago, but now, it has to be like 930 or 960 Turkish Liras. I am not sure. My husband is withdrawing the money so I am not sure about the exact amount of it. But it increased like 200 liras in 3 years."
(Sena, 32, Atasehir)

Hmm... I can't remember the exact amount of the cash-for-care that we were receiving 5 years ago... I think it is like 870 Turkish liras now, I am not sure. My husband is withdrawing the money, so I have no idea.
(Arzu, 35, Sultangazi)

Living with disability and caregiving can incur extra expenditures on items such as extra heating bills, special food, extra laundry and toiletry supplies, transport, and labour-saving and time-saving devices to ease the work of caregiving. These extra expenditures put a significant burden on the use of cash allowance by carers and constitute a higher share of household expenditures in low-income households. Of the 16 caregivers, half indicated they had unmet needs such as food, warm clothes and housing repairs. Because of the combination of their low income and the extra expenses for caring for a disabled child, they reported that they were simply unable to afford these basic items:

The rent on this house is 500 Turkish lira, which means that we are spending half amount of cash-for-care for our rent. We cannot afford to pay our water and electricity expenses. However, you cannot buy new, clean clothes for your children. Luckily, our disabled child only needs diapers, so he does not have that many additional needs and expenses.

(Fatma, 40, Atasehir, still receiving cash-for-care)

This money (referring to the amount cash-for-care) has been used only for our living expenses. I mean, natural gas, water, electricity... It is not related to my child's needs because before him, I have to survive first.

(Meryem, 35, Atasehir, still receiving cash-for-care)

When I asked the respondents on how they were spending the cash-for-care, a vast majority of the carers responded that they spend it on living expenses such as food, electricity, rent and water. However, many of the carers mentioned the needs of their disabled child as second when it comes to the spending arrangement. Of the 16 respondents, very limited number of caregivers reported that they had been spending the money only for the needs of their disabled child:

This money has been used for only the needs of our disabled child. I mean, the income of this whole family has been used for our children such as food, their needs etc. We cannot say 'no' to him. I would like to use this cash for our living expenses as well, but this is for him.

(Ayten, 45, Sultangazi, still receiving cash-for-care)

While Arzu told me the same thing, it can be seen that their socio-economic status is considerably lower than other families that I talked to:

My son has a vaccine which costs 500 Turkish liras. Because of the general health insurance, half of it is paid by the state, so we have to pay an extra 250 liras every month. We are using this money for our son's medicine in general. The rest of the money is spent on food, and especially on bread as we are living with 11 people in the house. However, we can only afford to buy stale bread.

(Arzu, 35, Sultangazi, still receiving cash-for-care)

For those who reported that the cash allowance is spent primarily on caring for their child with disabilities, most indicated that the needs were medicine, hygiene and toiletries. However, three out of four carers reported that the cash-for-care cannot be used for caring for their disabled child for two reasons. First, many of the carers have complained about the amount, although they reported that they were satisfied with the amount when I first asked the question at the beginning of the interview. However, what I observed from their answers to the question on their spending arrangement is that the vast majority of the carers realize that due to the extra caring costs related to their disabled child, they have been failing to satisfy the needs of their disabled child. Second, as the caregivers that I interviewed belong to the "poorest of the poor", the cash-for-care has been used for basic needs such as food, shelter and water to survive because of they have to live on low incomes.

4.6 Conclusion

Before making a further analysis of the fieldwork related to the existing literature, it would be meaningful to make a brief, technical summary of the caregivers' experience on the cash-for-care policy in terms of five different thematic areas:

application, attitude towards the cash scheme, the impact of the cash scheme, the care arrangement and spending arrangements.

First of all, the time of caregivers' first application and admission to the cash scheme are all different. The majority of the respondents learned about the policy from different sources. While a few of the caregivers found out about the policy from their friends who have been receiving cash-care-care for their disabled relatives, few of them learned on their own by researching online. While only one of the respondents learned about the policy with the guidance of a rehabilitation center, doctors informed few of them when they first went to a doctor for their disabled child. However, the majority of the respondents criticized the government and the Ministry of Family and Social Policy for the lack of information and communication with their citizens in terms of the regulation of social assistance schemes. While the majority of the respondents reported that they had visited by social workers at the beginning of the application process, few reported that they had witnessed such home visits, which is highly exceptional in terms of the required procedure of cash-for-care policy. One-fourth of the respondents also mentioned a negative experience on how they were discriminated against by the public officers during the application process.

The attitude towards the cash scheme can be summarized under two headings: the amount of cash and the additional support that comes with the allowance. Of the 16 caregivers, half of the respondents reported that they found the amount of cash allowance inadequate and that they had not seen this policy on a right-based approach; half of the respondents reported that they were satisfied with the amount and made religious comments. While very few numbers of caregivers indicated that the cash-for-care has been seen as "alms" in the eyes of the

government, the ones who emphasized that the amount of cash benefits should be the same as the minimum wage and that it should offer retirement pensions for the mothers of children with disabilities are very limited. When it comes to the question on any additional support, the results are quite interesting. Half of the respondents reported that they are totally against institutional care, adding that as long as they were living, they could not let their disabled child be cared for in an institutional setting instead of their own home. Of the respondents who are against institutional care, the ones who are satisfied with the amount of cash-for-care did not demand any additional support, and they would like to continue with the cash allowances; however, the ones who are unsatisfied with the amount of cash-for-care would like to receive home care services. However, the number of these people is still very low. One-fourth of the respondents did not even think about anything as additional support. While the market option came to the mind of some respondents, they indicated that their socio-economic status did not allow them to pay the cost of a formal caregiver with a professional background. They could not even conceive of a formal, professional caregiver which is publicly funded. To sum up, respondents generally took care of their disabled child at home by themselves, and by continuing to receive cash-for-care. With some exceptions, nothing came to mind when I asked about additional support for caring their children. Although the caregivers complained about the physical and psychological difficulties of caring for their disabled children, they could not provide any examples of an additional support for various reasons.

The impact of the cash allowance differs according to whether they beneficiaries were still receiving cash-for-care (versus those whose allowances had been cut off). In the first category, half of the respondents indicated that the cash-for-

care had a positive impact on their economic and social well-being. The other half emphasized that the cash allowance had neither a positive impact nor a negative one. However, the majority of the respondents emphasized that the cash-for-care is very helpful in their paying for general household expenses, not for the special needs of their disabled child. In the second category, the majority specified that their economic condition was affected in a negative way when the cash allowance was cut off. However, the others indicated that their economic situation had not changed because some family members had started to work in formal employment at the minimum wage which means that they lost the right to get the social assistance. Instead, they started to live with a better income.

In terms of care arrangements, it is possible to find commonalities. In all the households, mothers were the first primary caregivers of their disabled child. While the “women” such as daughters, mother-in-law and daughter-in-law could be considered secondary caregivers in Sultangazi, men, such as sons and fathers, were prevalent as caregivers along with women. When it comes to care arrangement in urgent cases, large families were luckier than smaller nuclear families in being able to leave their disabled child for a short time. If the number of family members is fewer than four, the women are likely to leave their disabled child with their mother-in-law or daughter-in-law when they have something urgent to do outside. Men are responsible for grocery shopping in the houses where a disabled child lives.

Although the concept of neighbourhood is very strong in the two districts, respondents reported that they were not in favour of leaving their disabled child with neighbours for a short time. The majority reported that they could not trust their neighbours to care for their children “tenderly” and “sufficiently” and indicated that their child could not feel comfortable outside their own house. Only two respondents

specified that they were lonely, and they started to work informally as cleaning ladies when their cash allowance was cut off and had to take along the disabled child when they went out.

Finally, the pattern of spending arrangements tells us something striking. As the beneficiaries of the cash-for-care scheme have to live on very low incomes, the amount of the cash allowance fails to meet the special needs of children with disabilities. The reason is that the cash allowance is used for basic household needs such as food, warm clothes and water. While only 3 respondents reported that the cash-for-care was used only for the special needs of their disabled child, the rest explicitly indicated that the cash allowance was used for household expenses in order to survive. Medicine, hygiene and toiletries were the top three mentioned special needs of the disabled child.

CHAPTER 5

CONCLUSION

The results of this fieldwork cannot be generalized as an outcome of the cash-for-care scheme targeting children with disabilities in Turkey's welfare regime.

However, the experiences and narratives of caregivers collected in this study are very valuable in understanding how beneficiaries perceive the cash-for-care scheme.

The fieldwork demonstrates that all the caregivers who have been receiving cash-for-care live on a low income and they have very low socioeconomic status within the Turkish context. Therefore, as Yeo and Moore (2003) and Emerson and Hatton (2007) discussed, the number of poor people who suffer from poverty is relatively higher in households where a person with disabilities lives. Therefore, poverty emerged as an important issue, considering that the vast majority of the families of children with disabilities expressed that they cannot even afford the minimum living conditions. These children face the risk of poor health and lack of access to education (Brooks-Gunn and Duncan, 1997; Bradshaw, 2001), which leads to a continuous process, resulting in exclusion from society because of poverty and discrimination related to the disability. The cash-for-care scheme targeting persons with disabilities in Turkey is aligned with other social assistance mechanisms in Turkey, which also target the "poorest of the poor." However, unlike cash-for-care scheme and with the exception of conditional cash transfers, all other social assistance benefits in Turkey have been delivered irregularly, and the amount of them have been generally low. Therefore, although the cash-for-care beneficiaries belong to the poorest of the poor segment of the society, they are relatively in a

better social position than other social assistance beneficiaries as they have been receiving the relatively high amount of cash allowance regularly.

In terms of the cost of caregiving, all the caregivers indicated that their disabled child required extra assistance in their daily life activities such as dressing and feeding, which is in line with the findings of Roberts and Lawton (2001). While the respondents were explaining their experiences with caring for their disabled child, they mentioned economic and emotional costs. As the cash-for-care scheme targets the lowest income group in the Turkish case, the beneficiaries comprise the lowest income level of the society, who cannot even afford to buy basic needs such as clothing and pay for utilities and rent. When this situation was discussed together with the fact that these caregivers are also responsible for caring for one of the most disadvantaged groups in society, the cost burden doubled. As Glendinning (1992) argues, the low-income families have been facing a higher burden than high-income families in caring for a disabled child. Although I did not ask any specific question on how caregivers assess their mental health status, the majority of the respondents suggested that they were feeling exhausted and lonely because of caring for their disabled child, which concurs with previous studies (Sloper & Turner, 1992; Altuntaş & Atasü-Topçuoğlu 2016; Özer, 2016).

Because the cash-for-care scheme in Turkey does not allow the beneficiary greater choice, flexibility or control over how their disabled child's needs are met (unlike the case in the UK), this financial support functions only as a social assistance for the cash beneficiary, without providing any additional care support from different agencies or professionals.

Caring for children with disabilities is an experience, which is very challenging, time consuming and frustrating (Read & Clements, 2001), and children with disabilities and their informal caregivers becoming marginalized (Appleton, 1997; Department of Health, 1998). In addition to the social isolation faced by children with disabilities, their primary caregivers have been also concerned about their own social isolation, as the cash-for-care scheme causes them to be “house-bound” while caring for their children.

What emerged from this study is that, the cash-for-care beneficiaries went through a difficult process in making an application for this scheme. However, the lack of communication and coordination mechanisms has been making the process difficult and have been extending the time, despite the fact that the needs of children with disabilities are urgent.

In terms of employment, the Turkish case is striking, and my findings corroborate the previous literature. Except for two, the respondents reported that they had never worked. When I asked why they had stayed out of the workforce, the answers were as follows: responsibility for housework, responsibility for caring for children and responsibility for the care of a disabled child.

The ones who had to leave their formal jobs also indicated the same reasons for losing their job. Therefore, it would be obvious to claim that the most common reason for deciding to stop work all together is the increasing amount of care work, which these carers were having to provide, which Glendinning's (1992) study also demonstrated.

Although I did not have the opportunity interview the fathers of children with disabilities, I learnt that the vast majority of them have been working either in formal

or informal jobs, which shows that they did not lose their jobs as a result of the increased care burden. Therefore, as mothers of children with disabilities were the respondents of my study, they were more likely to have left the labour force, making it possible for their husbands to continue working. The trend in Turkey is approximately the same as the trend in the world, as previous studies have demonstrated (Porterfield, 2002; Powers, 2003; Leiter, 2004). Therefore, as this study demonstrates, mothers of children with disabilities are more likely to be out of the labour force, and the majority of them have no chance to leave formal employment because they were not in it in the first place. Thus, this study found that mothers of children with disabilities have very low labour force participation compared to mothers without disabled children. It can be concluded that the Turkish case resemble the global trend in many aspects, especially with regard to the employment status of mothers of children with disabilities engaged in care work in Turkey, which previous studies have shown as well (Breslau, Salkever, and Staruch 1982; Erickson and Upshur 1989; Porterfield 2002). More comprehensively, it would be worth mentioning that caring for children with disabilities has a significant impact on mothers in terms of their participation in the labour market, even though they were informal carers within their household in Turkey's welfare regime.

The distinction between “neediness” (*ihitiyaç sahipliği*) and “destituteness” (*muhtaçlık*)” is another issue that is prominent in the Turkish context. The majority of informal caregivers specified that their disabled child was unable to live “independently”. While they were explaining a day with their disabled children, the majority of the caregivers used the terms “dependent”, “indigent” and “vulnerable” in describing their children. Therefore, it would be significant to argue that the caregivers see their disabled child as a “dependent” rather than a human being who

can live independently, which is very far from an independent living approach. However, the existing rationale can be contextualized with the prominent conservative discourse and social policy implications of the AKP, which maintains that the persons with disabilities should be respected as dependents, as Buğra (2012) also claims. The government has been providing the cash-for-care to its citizens with a destitution approach, instead of social-rights based one. The cash-for-care scheme has not been supporting a care ethic promoting independent living in Turkey's welfare regime.

The majority of studies suggest that cash-for-care schemes have a positive impact on the lives of cash beneficiaries, as they increase the beneficiaries' ability to make choices in line with an independent living approach, especially in the UK (Rummery, 2006; Blyth and Gardner, 2007). However, this is not how the cash-for-care scheme works in Turkey. Unlike the UK's direct payments scheme, which enables caregivers to buy care services from the regulated market to employ professional care workers and to spend the allowance on purchasing care services instead of spending it on household's needs, as Yeandle and Stiell (2008) mentioned, Turkey's cash-for-care scheme functions more like a social assistance scheme.

In fact, the Turkish cash-for-care scheme resembles a categorical social assistance. As a person who has to meet the three conditions (impairment level, need level and income level) in order to benefit from at-home care allowance, these categories have increased the stigmatizing effects of the social assistance scheme in Turkey, especially the cash-for-care scheme, as Yilmaz (2011) also mentions.

The eligibility for the Turkish cash-for-care scheme relies not only on need for care, but also on the income level of the household. What the fieldwork has

shown is that caregivers have been denied cash-for-care due to negligible increases in their income level, although they still call themselves “poor” and state that they are “unable to afford even the basic goods to survive”.

The vast majority have reported that they spend the cash for basic household needs such as food, warm clothes, electricity and rent and that it fails to meet the special needs of their disabled child. As there is no control mechanism that dictates how households use the cash allowance, beneficiaries are both “free” to decide where to spend this money, but in practice, they spend it on basic needs, as they are on very low incomes. Therefore, the cash-for-care scheme cannot move beyond a cash-based social assistance mechanism targeting poorest of the poor instead of a compensation for women’s informal labour force while caring their disabled child or a care support for persons with disabilities. What is striking is that even the caregivers in this study are aware that the cash-for-care scheme has been provided to the caregivers with the mentality of financial aid.

It is important to discuss the gendered impacts of the cash-for-care scheme within the care arrangements in Turkish social care regime towards children with disabilities. “Gendered” care work has been one of the key themes in this study, noting that Lewis (2002) and Rummery (2010) always emphasized this in explaining the common pattern of the commodified care work in most European countries. Although I did not restrict myself to interviewing only mothers of children with disabilities, what I observed is that all the primary caregivers of children with disabilities that I came across were women. The vast majority of these women have been facing common challenges as a result of the cash-for-care scheme’s gendered design, which has been regenerating inequalities in Turkey’s patriarchal society, and especially within the private sphere while caring for a disabled child. This finding is

also in line with the previous studies that show that the conservative familialism in Turkey's welfare regime assigns women a primary role as mothers to stay at home and to be responsible for caring for their children (Coşar and Yeğenoğlu, 2011; Ünal & Cindoğdu, 2013).

In the same way as childcare policies which previous studies have described (Ecevit, 2015; Toksöz, 2012; Buğra, 2012), care policies targeting persons with disabilities have aligned with the general trend in Turkey's welfare regime. In the last decade, it would be significant to claim that there is a trend towards de-institutionalisation of care services towards individuals with a disability, while promoting home-care with the cash-for-care policy in Turkey. While the international literature has also demonstrated that there are moves from state-led provision of institutional care services to cash-based systems for persons with disabilities across many countries, Turkey's experience differs from the case in other countries for various reasons. Along with the AKP's dominant policy and discourse about women on strengthening the social responsibility among them within the household, the primary caregivers are the females in the families, as this study also demonstrated.

I asked the caregivers who took over the caring responsibility for their disabled child when they had to go out for a limited time. The vast majority of caregivers mentioned that their husbands had been also helping to care for their child, but many of them listed a daughter, mother-in-law or daughter-in-law as the secondary-carer of their disabled child. However, there is an important fact that should not be ignored. The majority of households that I have visited were not comprised of nuclear families. There were at least four other family members living in the same household and this number reached 11 in one of the households. In these

cases, the vast majority of the caregivers indicated that going out for a limited time did not cause a problem, as their household is large. However, I am sure that making such a care arrangement would be very difficult for the households where a maximum 2-3 people were living. In this research, caregivers in these households have indicated that they cannot leave their children with someone in their household because they were living alone. In addition to this, types of disabilities of children may lead to differences in terms of the care needs and care arrangements within households as well. However, this factor was left out of the scope of this study.

As this is the case, the care work cannot be taken into the public sphere, and the gender inequalities have been regenerating within the private sphere, as the care work has become invisible. Considering the prominent approach of the social care regime in Turkey with the prior policy implementation towards the caregivers of children with disabilities, the gendered character of the social care regime overlaps with the cash-for-scheme explicitly, which promotes keeping women in the household to perform care work.

The cash beneficiaries' approach towards institutional care can be discussed with the care arrangements based on family values developed by Pfau-Effinger (2005). Care arrangements based on family values, those relying on the cultural values regarding the emphasis of family and the gendered division of labour are applicable to the prevalent care arrangement in Turkey's welfare regime in terms of caring for disabled children.

Care arrangements in families with a disabled child also affect the responsibilities of men, though much less than women. For example, as caregivers, women cannot get out of the house due to their full-time care responsibilities. My

married respondents stated that their husbands are responsible for the grocery shopping. This means that fatherhood roles have started to stand in the middle of breadwinning and homemaking when it comes to the households where there is a disabled child. While they have been participating in the labour force, which is associated with breadwinning, they have been also doing the grocery shopping, which is normally associated with women's homemaking.

This study demonstrated that the vast majority of caregivers were totally against the idea of institutional care. Their criticisms are mostly about the amount received. It would be obvious to claim that one of the biggest reasons behind this approach is the emphasis of strong familialism in Turkey's welfare regime through the policies and discourse. As Özateş (2015) also argues, although the conditions of at-home care allowances in Turkey are much heavier than in European welfare states given that the policy gives very limited options for informal caregivers to socialize, the caregivers accept the care burden which emerges as the consequence of cash-for-care. My respondents expressed the emotional costs of care burdens using phrases such as "isolation", "exhaustion" and "hopelessness" but immediately continued with the following phrase, "as long as I am alive, I will look after my child." What is striking is that, most respondents did not describe these challenges as a burden. On the contrary, they stated that they have been willingly sacrificing themselves as "proper mothers". Therefore, most caregivers of children with disabilities have employed the discourse that has presented motherhood a "sacred" job and this discourse contributed to the legitimacy of women-led care work in the private sphere with the regeneration of gender inequalities within the family.

The care work that has been carried out informally by women is seen as the norm among the caregivers, whereas the demand for a disabled child to be cared for

in care and rehabilitation centre is seen as deviant, as the institutions have been stigmatized with a negative image. What is also interesting here is that many of the caregivers could not even imagine an ideal, alternative care service that could be provided, even without lifting the cash-for-care. Although the majority of them reported that the cash-for-care scheme should continue with some improvements in terms of its amount, very few had a demand for professional carers. Even with respect to the amount of cash allowance, most caregivers accepted that it fails to meet the needs, the majority refrained from translating this criticism into a political demand. Still, they could not even imagine that these professional carers could be publicly funded so that they would not have to purchase that service from the market. As there has been no such state-funded professional home-care policy in modern Turkey's history, the caregivers could not even think of such a policy. Although there are many studies on the emergence of municipal care services towards children with disabilities in Istanbul (Çelebi, 2017), none of the caregivers mentioned any support that they received from the municipalities of Ataşehir and Sultangazi. Therefore, the cash beneficiaries' expectations remain limited to home care, along with the prevalent discourse of family solidarity, the privatization of care services and residual cash-based social assistance programmes.

To sum up, cash-for-care is the main social care policy in Turkey's welfare regime. As care work has been left to women in the private sphere, carers have been satisfied that they themselves are caring for their children within their own home, but they also criticizing the of cash-for-care, and they express the emotional costs of this model, along with their isolation and loneliness. In these circumstances, the cash-for-care has remained only as financial aid, or a cash transfer which definitely improves the economic conditions of the poor families where a disabled child exists. However,

it neither functions as a formal job for caregivers nor as care support for children with disabilities (and persons with disabilities in general). Caregivers who still receive cash-for-care as well as those whose cash benefit has been cut off have pointed out that they face many challenges while caring for their disabled children, which shows that the cash-for-care policy fails to serve as a care support scheme.

This cash scheme cannot be perceived as a compensation for caregivers' labour because the primary caregivers are not formally registered as labourers and because they do not have fixed working hours, time off, insurance or retirement. Therefore, the cash-for-care beneficiaries, most of whom are women, have remained as informal caregivers who are out of the labour market. Thus, it should be understood that institutional care and home care couldn't substitute for each other. They have to be taken as integrated with additional support from different professionals and agencies as well, while addressing new forms of care for children with disabilities.

5.1 Policy recommendations

In order to provide good qualified care, the cash-for-care scheme should be improved with a model of integrated social care services.

As the care work is left to the families in the current situation, the care burden is mainly on women. Instead of integrating disabled children and their informal carers into society, the current cash-for-care scheme in Turkey confines both the disabled person and his/her caregiver to their house. Therefore, there is a need for comprehensive social care policies that will enable both caregivers and care receivers to re-integrate into society and improve their abilities. Care options for persons with

disabilities should not be limited to institutional care and home care. Instead of offering incentives for private professional carers and care services, the government should be encouraged to develop a human resource capacity of publicly-funded professional carers who can provide qualified and standardized care for children with disabilities in their home. In this manner, receiving professional care services would be a social right for the citizens, and it would not require out-of-pocket expenditures for the families. Also, services such as nursing, day-care/round-the-clock care, and domestic work should be also integrated to the care services in order to lift the full responsibility of care work from only the caregiver. In addition, local authorities should provide such social care facilities for both caregivers and care receivers.

APPENDIX A

SEMI-STRUCTURED INTERVIEW QUESTIONS IN ENGLISH

A.1 Caregivers who have been receiving cash-for-care

1. How long have you been receiving cash-for-care?
2. Can you talk about the process to apply for cash-for-care schemes? How long did it take?
3. How does the cash-for-care bail your family out? Or does it bail you out?
4. What are the impacts of these cash transfers on your disabled child?
5. What are the impacts of these cash transfers on your economic condition? I mean, how did you feel before receiving this cash support, and how do you feel now? What conditions have changed?
6. What are the problems with the cash-for-care in terms of meeting the needs of your disabled child?
7. What type of support do you get instead of cash-for-care?
8. Suppose that while you are receiving cash-for-care, a public institution or a caregiver from an institution has appeared with additional support. What do you think about it?
9. What do you think about the amount of the cash-for-care? Do you think it is sufficient?
10. How do you arrange the care schemes within your family before receiving cash-for-care?
11. What is your typical day like? How do you spend your day?
12. What type of problems do you confront in a day while caring your disabled child?

13. Are there any other relatives or neighbors who care for your disabled child if you have to go out? If yes, how is it arranged?
14. As the caregiver of your disabled child, what do you think about being dependent on home care?
15. Have you worked before? If no, what do you think about being employed as a mother of a disabled child? Have you ever thought about it?
16. What about your husband's role in caring for your children?

A.2 Caregivers who lost their eligibility to receive cash-for-care

1. Can you talk about the application process for receiving cash-for-care? What problems did you experience during this process?
2. What were the reasons given by the ministry for not granting you cash-for-care? What did they tell you?
3. What type of support do you get instead of cash-for-care for caring for your disabled child?
4. Why do you want to receive cash-for-care?
5. If you could were eligible to receive cash-for-care, what would change?
6. What is your typical day like? How do you spend your day?
7. What type of problems do you confront in caring your children in a day?
8. When are you unable to satisfy the needs of your children?
9. Can you go out to visit your relatives or neighbors? I mean, how do you manage to go out? If you have to go out for shopping, how do you arrange the care of your children?
10. Have you worked before? If no, what would you think about being employed as a mother of disabled child? Have you ever thought about it?
11. What about your husband's role in caring for your children?

APPENDIX B

SEMI-STRUCTURED INTERVIEW QUESTIONS IN TURKISH

B.1 Evde bakım aylığından yararlanan bakım veren aileler

1. Ne kadar zamandır evde bakım aylığı alıyorsunuz?
2. Acaba biraz bu aylığı almaya hak kazanmak için geçen süreci anlatabilir misiniz? Ne kadar sürdü, nasıldı?
3. Engelli bakım aylığı ailenizde nasıl bir rahatlama sağladı, biraz anlatabilir misiniz?
4. Bu engelli bakım aylığının engelli oğlunuz/kızınız üzerindeki ne gibi etkileri oldu?
5. Ekonomik anlamda bu engelli bakım maaşının aileniz üzerindeki etkileri neler oldu? Yani bu aylığı almadan önce durumunuz neydi ve şimdiki durumunuz nedir? Şartlar nasıl değişti? Biraz bunlardan bahsedebilir misiniz?
6. Engelli çocuğunuzun özel ihtiyaçlarını karşılaması anlamında engelli bakım aylığı size yeterli olabildi mi? Faydalarını sıralayabilir misiniz?
7. Engelli bakım aylığı dışında herhangi bir destek alıyor musunuz? Alıyorsanız, ne gibi bir destek?
8. Varsayalım ki bu engelli bakım aylığını alırken bir başka kamu kurumu veya özel kurumdan bir bakımveren, size ek destek vermek istiyor. Böyle bir durum karşısında ne düşünürsünüz?
9. Engelli bakım aylığının miktarı hakkında ne düşünüyorsunuz?
10. Bu engelli bakım aylığını almadan önce ailenin her bireyi çocuğunuzla ilgileniyor muydu? Nasıl bir görev dağılımı vardı?

11. Bir gününüz nasıl geçiyor? Bana biraz anlatabilir misiniz?
12. Bir gün içerisinde çocuğunuzun bakımını sağlarken ne gibi problemlerle karşılaşıyorsunuz?
13. Evden çıkmanızın gerektiği durumlarda çocuğunuza bakabilecek olan bir yakınınız veya komşunuz var mı? Şöyle sorayım, evin dışında kendinizi nasıl organize ediyorsunuz? Örneğin çarşıya çıkmak zorunda kaldığımızda, engelli çocuğunuzun bakımını nasıl sağlıyorsunuz?
14. Önceden çalışıyor muydunuz? Çalışmadıysanız, hiç çalışmayı düşündünüz mü? Bunun hakkında ne düşünüyorsunuz?
15. Çocuğunuzun bakımı konusunda eşinizin rolü nedir?

B.2 Evde bakım aylığı kesilen bakım veren aileler

1. Bana biraz evde bakım aylığından yararlanabilmek için geçen süreci anlatabilir misiniz? Bu sürede ne gibi problemlerle karşılaştınız?
2. Hangi nedenlerden dolayı engelli bakım aylığı almaya hak kazanamadınız? Bakanlık bunun gerekçesini ne olarak açıkladı?
3. Çocuğunuzun bakımı için evde bakım aylığı yerine ne gibi bir destek alıyorsunuz?
4. Neden evde bakım aylığı desteğinden yararlanmak istiyorsunuz?
5. Eğer engelli bakım aylığı almaya hak kazansaydınız, sizce hayatınızda neler değişirdi?
6. Bir gününüz nasıl geçiyor? Bana biraz anlatabilir misiniz?
7. Bir gün içerisinde çocuğunuzun bakımını sağlarken ne gibi problemlerle karşılaşıyorsunuz?
8. Çocuğunuzun ihtiyaçlarını karşılarlarken ne gibi durumlarda yetersiz kaldığımızı hissediyorsunuz?

9. Akrabalarınız, arkadaşlarınız veya komşularınızla dışarı çıkabiliyor musunuz? Şöyle sorayım, evin dışında kendinizi nasıl organize ediyorsunuz? Örneğin çarşıya çıkmak zorunda kaldığınızda, engelli çocuğunuzun bakımını nasıl sağlıyorsunuz?
10. Önceden çalışıyor muydunuz? Çalışmadıysanız, hiç çalışmak istediniz mi? Bunun hakkında ne düşünüyorsunuz?
11. Çocuğunuzun bakımı konusunda eşinizin rolü nedir?



REFERENCES

- Acar, F., & Altunok, G. (2015). Neo-liberalizm ve neo-muhafazakarlık ekseninde Türkiye'de özel alan politikası. In S. Dedeoğlu, & A. Elveren, *2000'ler Türkiye'sinde sosyal politika ve toplumsal cinsiyet* (pp. 23-63). Ankara: İmge Kitapevi.
- Altuntaş, B., & Atasü-Topçuoğlu, R. (2016). *Engelli bakımı: Sosyal bakım ve kadın emeği*. Ankara: Nika.
- Anttonen, A., & Sipilä, J. (1996). European social care services: Is it possible to identify models? *Journal of European Social Policy*, 6(2), 87-100.
- Baldwin, S. (1985). *The costs of caring: Families with disabled children*. London: Routledge.
- Baxter, C. (1987). Professional services as support: Perceptions of parents. *Australia and New Zealand Journal of Developmental Disabilities*, 13(4), 243-253.
- Benjamin, A., Mattias, R., & Franke, T. (2000). Comparing consumer-directed and agency models for providing supportive services at home. 35(1 Pt 2), *Health Services*, 351-366.
- Bettio, F., & Plantenga, J. (2004). Comparing care regimes in Europe. *Feminist Economics*, 10(1), 85-113.
- Blyth, C., & Gardner, A. (2007). 'We're not asking for anything special': Direct payments and the carers of disabled children. *Disability & Society*, 22(3), 235-249.
- Bradshaw, J. (2001). Complexity of staff communication and reported level of understanding skills in adults with intellectual disability. *Journal of Intellectual Disability Research*, 45(Pt 3), 233-243.
- Breslau, N., Salkever, D., & Staruch, K. (1982). Women's labor force activity and responsibilities for disabled dependents: A study of families with disabled children. *Journal of Health and Social Behavior*, 23(2), 169-183.
- Buğra, A. (2012). Türkiye'nin değişen refah rejimi: Neoliberalizm, kültürel muhafazakarlık ve yeniden tanımlanan toplumsal dayanışma. In S. Dedeoğlu, & A. Elveren, *Türkiye'de refah devleti ve kadın* (pp. 47-71). İstanbul: İletişim.
- Buğra, A., & Keyder, Ç. (2006). The Turkish welfare regime in transformation. *Journal of European Social Policy*, 16(3), 211-228.
- Buğra, A., & Yakut-Çakar, B. (2010). Structural change, the social policy environment and female employment in Turkey. *Development and Change*, 41(3), 517-538.
- Casey, B. et al. (2003), "Policies for an ageing society: Recent measures and areas for further reform", OECD Economics Department Working Papers, No. 369, OECD publishing, OECD.

- Clark, H., Hough, H., & Macfarlane, A. (2004). *'It pays dividends': Direct payments and older people*. Bristol: Policy Press.
- Cohen, P., & Petrescu-Prakova, M. (2006). Gendered living arrangements among children with disabilities. *Journal of Marriage and Family*, 68(3), 630-638.
- Connors, C., & Stalker, K. (2003). *The views and experiences of disabled children: A positive outlook*. London: Jessica Kingsley.
- Coşar, S., & Yeğenoğlu, M. (2011). New grounds for patriarchy in Turkey? Gender policy in the age of AKP. *South European Society and Politics*, 16(4), 555-573.
- Çarkoğlu, A., Kafescioğlu, N., & Akdaş Mitrani, A. (2012). Review of explicit family policies in Turkey from a systemic perspective. *Journal of Child and Family Studies*, 21(1), 42-52.
- Çelebi, E. (2017). *The local welfare system in Turkey: The case of municipal care services in Istanbul*. (Unpublished master's thesis). Bogazici University, Istanbul, Turkey.
- Çitak, Z., & Tür, Ö. (2008). Women between tradition and change: The Justice and Development Party experience in Turkey. *Middle Eastern Studies*, 44(3), 455-469.
- Da Roit, B., Le Bihan, B., & Österle, A. (2008). Long-term care policies in Italy, Austria and France: Variations in cash-for-care Scheme. In B. Palier, & C. Martin, *Reforming the bismarckian welfare systems* (pp. 117-136). Blackwell.
- Daly, M. (2002). Care as a good for social policy. *Journal of Social Policy*, 31(2), 251-70.
- Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *British Journal of Sociology*, 51(2), 281-298.
- Della Porta, D., & Keating, M. (2008). *Approaches and methodologies in the social sciences: A pluralist perspective*. New York: Cambridge University Press.
- Dobson, B., & Middleton, S. (1998). *Paying to care: The cost of childhood disability*. York: YPS for the Joseph Rowntree Foundation.
- Donnellan, C. (2001). *Disability rights*. London: Independence.
- Ecevit, Y. (2015). Feminist sosyal politika bağlamında Türkiye'de çocuk bakımı ve eğitimine iki paradigmadan doğru bakmak. In A. Makal, & G. Toksöz, *Geçmişten günümüze Türkiye'de kadın emeği* (pp. 185-223). Ankara: İmge Yayınevi.
- Ekim-Akkan, B. (2010). Sosyal hak talebi olarak bakım ihtiyacı. In P. Uyan-Semerci, *İnsan hakları ihlali olarak yoksulluk* (pp. 57-70). İstanbul: İstanbul Bilgi Üniversitesi.
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, 191(6), 493-499.

- Erickson, M., & Upshur, C. C. (1989). Caretaking burden and social support: Comparison of mothers of infants with and without disabilities. *American Journal on Mental Retardation*, 94(3), 250-258.
- Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Cambridge: Polity Press.
- Evren, C. (2012). *Assessing the disabled, making 'the state'*. (Unpublished master's thesis). Bogazici University, Istanbul, Turkey.
- Galvin, R. (2004). Challenging the need for gratitude: Comparisons between paid and unpaid care for disabled people. *Journal of Sociology*, 40(2), 137-155.
- Geissler, B., & Pfau-Effinger, B. (2005). Change in European care arrangements. In B. Pfau-Effinger, & B. Geissler, *Care and social integration in European societies* (pp. 3-21). Bristol: The Policy Press.
- Glendinning, C. (1992). *The costs of informal care: Looking inside the household*. London: HMSO.
- Glendinning, C., & Kemp, P. (2006). *Cash and care: Policy challenges in the welfare state*. Bristol: The Polity Press.
- Hürriyet. (2015, January 2). *Sağlık Bakanı Müezzinoğlu: Anelik bir kariyerdir*. Retrieved April 28, 2016, from <http://www.hurriyet.com.tr/saglik-bakani-muezzinoglu-annelik-bir-kariyerdir-27882199>
- İlkkaracan, İ., Kim, K., & Kaya, T. (2015, August). The impact of public investment in social care services on employment, gender equality, and poverty: The Turkish case. (<http://www.tr.undp.org/content/dam/turkey/docs/povreddoc/rapor-son-eng..pdf>)
- Kılıç, A. (2010). Gender, family and children at the crossroads of social policy reform in Turkey: Alternating between familialism and individualism. In M. Ajzenstadt, & J. Gal, *Children, gender and families in Mediterranean welfare states* (pp. 165-179). London: Springer.
- Knijn, T. and Kremer, M. (1997). Gender and the caring dimension of the welfare states: Towards inclusive citizenship. *Social Politics*, 4(3), 328-362.
- Leiter, V., & Krauss, M. (2004). Claims, barriers, and satisfaction: Parents' requests for additional special education services. *Journal of Disability Policy Studies*, 15(3), 135-146.
- Lewis, J. (2002). Gender and welfare state change. *European Societies*, 4(4), 331-357.
- Morris, J. (1996). *Encounters with strangers: Feminism and disability*. London: The Women's Press.
- Özateş, Ö. (2015). *Malumun ilanı: Kadın emeğinin saklı yüzü - Ev içi bakım emeği*. Ankara: Nota Bene Yayınları.

- Özer, M. M. (2016). *Toplumsal cinsiyet bağlamında Türkiye’de ücretli evde bakım uygulamasının değerlendirilmesi*. (Unpublished master’s thesis). Kocaeli University, Kocaeli, Turkey.
- Pfau-Effinger, B. (2005a). Development paths of care arrangements in the framework of family values and welfare values. In B. Pfau-Effinger, & B. Geissler, *Care and social integration in European societies* (pp. 21-49). Bristol: The Policy Press.
- Pfau-Effinger, B. (2005b). Welfare state policies, cultural differences and care arrangements. *European Societies*, 7(2), 321-341.
- Pfau-Effinger, B. (2004). *Development of culture, welfare states and women's employment in Europe*. Aldershot: Ashgate.
- Porterfield, S. (2002). Work choices of mothers in families with children with disabilities. *Journal of Marriage and Family*, 64(4), 972–981.
- Read, J., & Clements, L. (2001). *Disabled children and the law: Research and good practice*. London: Jessica Kingsley.
- Republic of Turkey. *Bakıma Muhtaç Özürlülerin Tespiti ve Bakım Hizmeti Esaslarının Belirlenmesine İlişkin Yönetmelik*. Promulgated in 30 July 2006, Announced in the Official Gazette no. 26244.
- Republic of Turkey, Directorate General of Services for Persons with Disabilities and the Elderly. (July, 2017). *Engelli ve Yaşlı Bireylere İlişkin İstatistik Bilgiler*. Retrieved May 24, 2017, from <http://eyh.aile.gov.tr/data/56179f30369dc5726c063e73/b%C3%BClten-temmuz2017.pdf>
- Roberts, K., & Lawton, D. (2001). Acknowledging the extra care parents give their disabled children. *Child: Care, Health and Development*, 27(4), 307-319.
- Rummery, K. (2010). A comparative discussion of the gendered implications of cash-for-care schemes: Markets, independence and social citizenship in crisis? In B. Greve, *Choice: Challenges and perspectives for the European welfare states* (pp. 94-108). West Sussex: Wiley-Blackwell.
- Rummery, K. (2006). Disabled citizens and social exclusion: the role of direct payments. *Policy and Politics*, 34(4), 633–650.
- Schneider, U., & Reyes, C. (2007). Mixed blessings: Long-term care benefits in Germany. In C. Ungerson, & S. Yeandle, *Cash for care in developed welfare states* (pp. 137-166). London: Palgrave Macmillan.
- Scott, E. (2010). ‘I feel as if I am the one who is disabled’: The emotional impact of changed employment trajectories of mothers caring for children with disabilities. *Gender and Society*, 24(5), 672–696.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, 18(5), 259-282.

- Stainton, T., & Boyce, S. (2004). 'I have got my life back': Users' experience of direct payments. *Disability & Society*, 19(5), 443-454.
- Stetson, D., & Mazur, A. (1995). *Comparative state feminism*. London: Sage.
- The Guardian. (2014, November 24). *Recep Tayyip Erdoğan: 'women not equal to men'*. Retrieved May 10, 2016, from The Guardian :
<http://www.theguardian.com/world/2014/nov/24/turkeys-president-recep-tayyip-erdogan-women-not-equal-men>
- TIME. (2016, March 8). *Turkey's Erdogan Says 'A Woman Is Above All A Mother'*. Retrieved January 12, 2018, from <http://time.com/4250853/turkey-recep-tayyip-erdogan-a-woman-is-above-all-a-mother/>
- Timonen, V., Convery, J., & Cahill, S. (2006). Care revolutions in the making? A comparison of cash-for-care programmes in four European countries. *Ageing and Society*, 26(3), 455-474.
- Toksöz, G. (2012). Neoliberal piyasa, özel ve kamusal patriyarka çıkmazında kadın emeği. In S. Dedeoğlu, & A. Elveren, *Türkiye'de refah devleti ve kadın* (pp. 103-127). İstanbul: İletişim.
- Toksöz, G. (2011). *Kalkınmada kadın emeği*. İstanbul: Varlık Yayınları.
- TURKSTAT. (2015). *Time Use Survey*. Retrieved 2016, from TURKSTAT:
http://www.turkstat.gov.tr/PreTablo.do?alt_id=1009
- Unal, D., & Cindoglu, D. (2013). Reproductive citizenship in Turkey: Abortion chronicles. *Women's Studies International Forum*, 38, 21-31.,
- Ungerson, C. (2004). Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes. *Ageing and Society*, 24(2), 189-212.
- Ungerson, C., & Yeandle, S. (2007). Conceptualizing cash for care: The origins of contemporary debates. In C. Ungerson, & S. Yeandle, *Cash for care in developed welfare states* (pp. 1-13). Palgrave Macmillan.
- Widdows, J. (1997). *A special need for inclusion - Children with disabilities, their families and everyday life*. London: The Children's Society.
- World Bank. (2015). Supply and demand for child care services in Turkey: A mixed methods study. Washington, D.C.: World Bank Group.
(<http://documents.worldbank.org/curated/en/114451467999711217/Supply-and-demand-for-child-care-services-in-Turkey-a-mixed-methods-study>)
- Yazıcı, B. (2012). The return to the family: Welfare, state, and politics of the family in Turkey. *Anthropological Quarterly*, 85(1), 103-140.

- Yeandle, S., & Stiell, B. (2007). Issues in the development of the direct payments scheme for older people in England. In C. Ungerson, & S. Yeandle, *Cash for care in developed welfare states* (pp. 104-137). London: Palgrave Macmillan.
- Yeo, R. & Moore, K. (2003). Including disabled people in poverty reduction work: “Nothing about us without us”. *World Development*, 31(3), 571-590.
- Yılmaz, V. (2011). *The political economy of disability in Turkey: Disability and social policy reform in Turkey*. Germany: Lambert.
- Yılmaz, V. & Yentürk, N. (2017). Türkiye’de engellilere yönelik kamu harcamalarının on yıllık seyri. *Çalışma ve Toplum*, 2017/1, 59-74.
- Yılmaz, V., & Yentürk, N. (2012). *STK’lar için engellilere yönelik harcamaları izleme kılavuzu*. İstanbul: İstanbul Bilgi Üniversitesi Yayınları.

