FUTURE PLANNING AND SOCIAL POLICY EXPECTATIONS OF FAMILIES WITH CHILDREN WITH DOWN SYNDROME

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of Families with Children with Down Syndrome

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DECLARATION OF ORIGINALITY

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- this thesis contains no material that has been submitted or accepted for a degree or diploma in any other educational institution;
- this is a true copy of the thesis approved by my advisor and thesis committee at Boğaziçi University, including final revisions required by them.

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ABSTRACT

Future Planning and Social Policy Expectations

of Families with Children with Down Syndrome

What are the future care planning and social policy expectations of mothers who have been caring for their children with intellectual disabilities throughout their lives, in cases where they cannot continue to care for their children? This research question guided the current study, which specifically focused on Down syndrome in the context of intellectual disabilities. Using a qualitative design, data were analyzed thematically based on semi-structured, in-depth interviews with 16 mothers of children with Down syndrome living in Istanbul. As a result of the current study, financial and housing issues come to the fore in mothers' future care planning and social policy expectations for their children with Down syndrome. It is seen that mothers tend to leave as much cash and/or cash-convertible resources as possible for their children's future. In parallel, mothers' social policy expectations included regular cash transfers to ensure a decent standard of living for their children. Regarding residential and housing issues, mothers have a consensus that they want an arrangement where their children's current routines are least affected. Mothers also emphasized a preference for care to continue in the child's familiar home environment, ideally supported by known caregivers. Institutional care was considered only when necessary and as a last option. The findings indicate that mothers question the adequacy and scope of current social policies regarding future care. The study emphasizes the need for social policies that include individualized care plans. These expectations were discussed in relation to current practices in Turkey.

ÖZET

Down Sendromlu Çocuğa Sahip Ailelerin Gelecek Planlamaları ve Sosyal Politika Beklentileri

Zihinsel engelli çocukları olan annelerin, çocuklarına bakım vermeye devam edemedikleri durumlarda, çocuklarına ilişkin gelecek bakım planları ve sosyal politika beklentileri nelerdir? Bu araştırma sorusu, zihinsel engellilik bağlamında Down sendromuna odaklanan mevcut çalışmaya rehberlik etmiştir. Nitel desenle tasarlanan bu çalışmada, veriler İstanbul'da yaşayan ve Down sendromlu çocuğu olan 16 anneyle gerçekleştirilen yarı yapılandırılmış derinlemesine görüşmelere dayanarak tematik analiz yöntemiyle incelenmiştir. Araştırma sonucunda, annelerin Down sendromlu çocuklarına yönelik gelecek bakım planlamaları ve sosyal politika beklentilerinde finansal ve barınma ile ilgili meseleler ön plana çıkmıştır. Annelerin çocuklarının geleceği için mümkün olduğunca fazla nakit ve/veya nakde dönüştürülebilir kaynak bırakma eğiliminde olduğu görülmektedir. Buna paralel olarak, annelerin sosyal politika beklentileri arasında çocukları için makul bir yaşam standardı sağlamak için düzenli nakit transferleri yer almaktadır. Barınma söz konusu olduğunda ise anneler, çocuklarının mevcut rutinlerinin en az etkileneceği bir düzenleme istedikleri konusunda fikir birliğine sahiptirler. Bakım sürecinin çocuğun aşina olduğu ev ortamında devam etmesi isteği ve potansiyel bakımverenler vurgulanmıştır. Kurumsal bakım yalnızca gerekli durumlarda ve son seçenek olarak değerlendirilmiştir. Bulgular, annelerin gelecekteki bakıma ilişkin mevcut sosyal politikaların yeterliliğini ve kapsamını sorguladığını göstermektedir. Bireyselleştirilmiş bakım planını da içeren sosyal politikaların gerekliliği vurgulanmış ve bu beklentiler Türkiye'deki güncel uygulamalar ışığında tartışılmıştır.

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ABBREVIATIONS

AKP	Justice and Development Party
ASHB	Republic of Turkey Ministry of Family and Social Services
ÇÖZGER	Special Needs Evaluation Report for Children
DS	Down Syndrome
ICF	International Classification of Functioning, Disability and Health
PwD	People with Disabilities
PwID	People with Intellectual Disabilities
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

Care is a fundamental human activity that requires a comprehensive approach that addresses the needs of people of all ages and health conditions. In its broadest sense, care can be defined as all actions we take to sustain our lives and improve the world we live in in ways that enhance human well-being (Fisher & Tronto, 1990). Everyone may experience both needing care and providing care at some point in their lives (Akkan, 2022; Dowling, 2021; Knijn & Kremer, 1997).

The meaning of care varies depending on its context. Care can be defined as the provision of what is necessary for the health, welfare, and protection of an individual or entity. It encompasses a wide range of actions and attitudes aimed at promoting the well-being of people, groups, or even the environment. Slote (2007) contends that at the core of what we define as care lies empathy and the recognition of the significance of another person's situation, which involves both a degree of responsibility for his or her well-being and an interest in their life.

Another important aspect of care is that it is recognized as a form of labor, primarily directed toward meeting the needs of others (Harrington-Meyer, 2002; Ungerson, 2000). Care is time-consuming and often physically demanding (Pope et al., 2022). Unlike other types of work, care must both benefit the recipient and avoid causing harm (McKechnie & Kohn, 1999).

Care is also viewed as a social relationship (Lloyd, 2000), distinguishing it from other types of work. The care relationship can be both intimate, familial and enduring. At the same time, it may also be occupational in nature, focusing primarily or exclusively on mental and physical well-being, and may be limited in duration

(Lloyd, 2000). Care can be defined as, at its core, a relational concept and includes interdependent relationships and practices. Still, there are difficulties in drawing the boundaries of care labor in the context of its relational dimension and emerging needs (Akkan, 2022; Dowling, 2021).

Moreover, care is an inherently social activity that connects the state and society (Daly, 2002). In addition to being a human right, care is also a social right that the state must provide to its citizens. Considering the social right dimension of care, it is a political issue that belongs to the public sphere. In other words, it is beyond the family or other relatives of the person in need and is not limited to the private sphere (Akkan, 2010; Sennet, 2003). The government can fulfil its obligation of care for its citizens in need through the social policies and services it will produce for care issues (Akkan, 2010; Altuntaş & Atasü-Topçuoğlu, 2016). Care should be reformed within a citizenship framework that emphasises choice over market forces, enabling self-determination and social participation for both caregivers and recipients (Rummery & Fine, 2012). Care also refers to specific domains, such as disability care, elderly care, and childcare, among others. However, in accordance with the purpose of the current study, emphasis is placed on disability care within the umbrella concept of care.

People with disabilities (PwD) also need care just like everyone else, and it is essential to develop care policies that will include personal care and psychosocial support services for PwD who need care in their daily lives. Care-related policies are crucial for PwD because such policies can provide the needed support and assistance to live independent, fulfilling lives (Shaghashvili, 2022). Care policies can help ensure that PwD have access to necessary healthcare, education, and social services to manage their disability and participate fully in society. Additionally, care policies

can provide support to both the care receivers and the caregivers who provide care to PwD, helping to ensure that these individuals are able to continue providing care without experiencing burnout or other negative consequences (Shaghashvili, 2022).

Concerning disability research, the social model explains the exclusion of PwD from all domains of life based on social obstacles rather than mental differences or bodily differences (Oliver, 2013). This approach paved the way to understand problems that PwD face from a human rights perspective, including social rights, too (Bunbury, 2019). Although persistent inequalities in the private spheres are generally invisible, the social model can challenge the distinction between public and private spheres (Morris, 1996). Accordingly, the approach of care policies can help improve the lives of PwD and promote their inclusion and participation in society. By addressing care in policy, governments can ensure that PwD have the same opportunities and rights as other citizens in the society and can help reduce the barriers and discrimination PwD may face (Republic of Turkey Ministry of Family and Social Services [Aile ve Sosyal Hizmetler Bakanlığı] [ASHB], 2023a). Disability care-related policies can show complex features as a part of social policies, as they shape the human relations and motivations between caregivers and receivers, as well as determining the boundaries between the state, family, private secto, and non-governmental actors (Dolu, 2019).

In light of these conditions, this chapter mainly comprises the significance and purpose of the current study; afterwards, the outline of the chapters has been stated.

1.1 Significance of the research

Parenting, a transformative journey marked by profound adjustments and responsibilities, is a multifaceted experience that imparts both fulfilment and

challenges (Köksal, 2011). The decision to have a child is a complex and demanding responsibility for all parents, which is not only the advent of a new life but also an intricate shift in their lifestyle. Notably, when people have children with disabilities, there may be different processes, concerns, and expectations compared to other parents (Alpöge, 2012; Dervishaliaj & Murati, 2014; Pacis, 2023). In particular, the concept of caregiving takes on a distinctive dimension within the context of parents raising children with disabilities, as they must navigate the demands of daily life while simultaneously grappling with the special challenges posed by their children's experiences (Azar & Badr, 2010).

The experiences and challenges faced by PwD, including those with intellectual disabilities, are diverse and can vary depending on various factors such as societal attitudes, accessibility, support systems, and individual circumstances. However, it is crucial to note that historically, people with intellectual disabilities (PwID) have often faced significant stigma and discrimination (Anderson & Bigby, 2016). This discrimination can result in limited access to education, care, employment opportunities, healthcare, and social inclusion (Clifford Simplican, 2018; Ditchman et al., 2016; Meyers et al., 2023). Furthermore, negative stereotypes and misconceptions about PwID can contribute to marginalisation and disadvantages. From this perspective, some disabilities may be considered more severe or debilitating than others, contributing to stigmatization and discrimination towards individuals with certain disabilities (Stewart, 2004). Additionally, certain disabilities may receive more attention and resources, while others receive comparatively less (Meyers et al., 2023).

These research questions shaped the current study: What happens to children when mothers, who are usually the primary caregivers, cannot continue to care for

their children with intellectual disabilities? What are the future care plans and social policy expectations of mothers who have cared for children with intellectual disabilities throughout their lives for their children when the mothers cannot continue their care? The main focus of this study is to find answers to these questions, with a particular focus on people with Down syndrome (DS) and their caregivers.

PwID are a highly heterogeneous group; each syndrome and its related conditions have diverse characteristics and requirements, which affect life expectancy (Coppus, 2013). Therefore, examining specific and common syndromes that make up an important portion of intellectual disability is meaningful. DS is known to be the most common syndrome (World Health Organization [WHO], 2000), and the current study focuses on DS.

Coppus (2013) summarises the core literature about the life expectancy of the most common intellectual disability types and their unique features. Although the life expectancy of PwID is consistently lower than the average population because of other possible severe and multiple diseases, life expectancy has also increased overall for PwID. Recent data on the life expectancy of the most common types of intellectual disabilities show that individuals can live into adulthood and sometimes even into old age (Coppus, 2013).

For example, Table 1 shows medical records for PwID between 1930 and 1980, revealing extended years of life expectancy for PwID. Indeed, the data show that recent lifespan expectancies differ significantly from those in the 1930s, when children with DS or other intellectual disabilities rarely reached adulthood and died at an average age of 18.5 years (Carter & Jancar, 1983). Nonetheless, at present, individuals with DS can experience adulthood approximately into their 50s and 60s

(Baird & Sadovnick, 1987; Bittles et al., 2007; Covelli et al., 2016; Motegi et al., 2021; Presson et al., 2013; Yang et al., 2002).

Table 1. Average Age at Death (years), 1930-1980

Period	All Patients		Down Syndrome	
	Males	Females	Males	Females
1931-35	14.9	22.0	9.9	12.0
1936-40	15.7	26.3	12.2	13.6
1941-45	20.0	22.1	15.3	16.6
1946-50	21.9	30.1	18.2	18.9
1951-55	29.2	36.3	20.6	24.4
1956-60	34.4	43.9	31.0	31.0
1961-65	34.6	46.7	32.0	40.2
1966-70	40.6	46.7	31.3	35.5
1971-75	49.8	54.1	41.8	47.4
1976-80	58.3	59.8	55.3	52.7

(Carter & Jancar, 1983)

People with DS can have various health problems that become more severe as they age. These problems can be listed as heart defects, stomach and intestinal issues, immune system disorders, endocrine problems, obesity, spine problems, leukemia, dementia, dental problems, ear infections and hearing and vision problems (Baumer et al., 2023; Heinke et al., 2021; Turkish Fetal Medicine and Perinatology Association, 2020). Although not all PwID have equal opportunities to achieve old age, their life expectancy most likely will continue to increase, and many individuals

may live as long as the general population (World Health Organization [WHO], 2000). In addition, congenital disorders (birth defects) can contribute to long-term disability (World Health Organization [WHO], 2023); globally, an estimated 8 million newborns are born with birth defects each year (Singh, 2023).

However, there is also a noticeable reduction in the number of babies who die before the age of one (Kucik et al., 2013; Presson et al., 2013; Shin et al., 2007). Correspondingly, a small but significant portion of the increasing number of adults in societies will be composed of older PwID who need care (Coppus, 2013). Moreover, the relationship between aging and disability has become more prominent everywhere since the potential for disability increases in old age (World Health Organization & World Bank, 2011).

The significance of the current study is emphasised in the context of extended life spans and the need to develop policy arrangements to address the changing needs of PwID throughout their lives, specifically those with DS.

In line with this, caregivers are also as heterogeneous a group as the people they care for; for example, they can be older or younger. It can be assumed that if care is delivered by a family member, the caregivers of children with intellectual disabilities will be older individuals. Also, the number of older carers is expanding rapidly as the world's population ages (Greenwood et al., 2019; Prosser & Moss, 1996). When caregivers are parents and the care receivers are children, ascribing adulthood to their children may be difficult for the parents, depending on the children's disability type. In cases where the need for support remains, PwID can be evaluated as eternal children (Baron et al., 1999). In this case, the person with a disability is stuck in eternal youth and eternal adulthood is ascribed to then parents, thus causing their transition into old age to differ from their peers (Engwall, 2017).

Age is an important variable that affects the caregiver's health conditions, and its influence on the caregivers' health should not be underestimated or disregarded. However, the caregiver's poor health is also associated with lower socioeconomic status and the care recipients' behavioral problems (Pinquart & Sorensen, 2007). The interlink between the health and wellbeing of the caregiver and the challenging behaviors of the care recipient is supported by several studies (Pinquart & Sorensen, 2007; Totsika et al., 2017). Although caregivers of PwID did not attribute their poor physical health to caregiving, they reported worse physical health than other caregivers (Totsika et al., 2017). Besides, they appear to suffer from poorer mental health outcomes than other carers do (Grey et al., 2018). In line with this, caregivers of PwID provide both care for longer and/or throughout their lifetimes (Walker & Walker, 1998), and declining health is associated with continuing caregiving (McCann et al., 2004).

Moreover, parents generally insist on being responsible for their children with intellectual disabilities until they are no longer able to provide care (Pryce et al., 2017). In other words, although parents acknowledged they could not care forever, most parents assumed that they would continue the care as long as they were alive (Pryce et al., 2017). Since care needs of PwID will not decrease after their parents are gone or suffer from illness, future planning for care is vital for those PwID to be able to sustain their lives.

Although thinking about the future is a complex process in multiple ways, inevitable life events make future care planning compulsory (Pryce et al., 2017) because the care uncertainty can be dealt with by preparing future planning and social policies (Garnham et al., 2019). In parallel, it is crucial that future care of

PwID should be planned while the current caregivers are alive and healthy (Chow, 2017).

In light of this, the following research questions shaped the current study: What happens to children when mothers, who are usually the primary caregivers, cannot continue to care for their children with intellectual disabilities? What are the future care plans and social policy expectations of mothers who have cared for children with intellectual disabilities throughout their lives, for their children when the mothers cannot continue their care? The main focus of this study is to find answers to these questions, with a particular focus on people with Down syndrome (DS) and their caregivers.

1.2 Purpose of the study

It is known that caregivers (usually mothers) continue to take on their "caregiving role" for as long as possible (Atasü-Topcuoğlu, 2022; Cantero-Garlito et al., 2020; Garnham et al., 2019; Sharma, 2016). Thus, the perspectives of caregivers and care receivers on early identification of needs for future care planning are unknown (Kruithof et al., 2021). However, the importance of care may increase unexpectedly for PwID in many aspects after inevitable life events, which may pose challenges with adaptation to change and coping with loss. In parallel, it is crucial that future care of PwID should be planned when the current caregivers are still alive and healthy.

The purpose of the current study is to explore the future planning and social policy expectations of mothers with children with DS. Although the cause of DS is not precisely known, generally, it is associated with advanced maternal age (age >35 years) (Glick et al., 2021; United Nations [UN], 2015; Musdalipa et al., 2021). In

recent decades, due to various factors, developed nations have seen a rise in the typical age at which women conceive and give birth (United Nations [UN], 2015; United Nations Economic Commission for Europe [UNECE], 2023). In parallel, when birth statistics in Turkey were examined, the average age of mothers who gave birth in 2001 was 26.7, which became 29.1 in 2021 (Turkish Statistical Institute [TUIK], 2021).

Accordingly, in a perspective where the possibility of giving birth to a child with DS is linked to the advancing ages of the mother. It can be thought that the possibility of giving birth to a child with DS is increasing (Aprigio et al., 2023). Therefore, given that DS is the most common syndrome in the context of intellectual disability (World Health Organization [WHO], 2000), and considering the increasing trend in the age of childbirth in relation to the probability of giving birth to a child with DS (Glick et al., 2021; United Nations [UN], 2015; Musdalipa et al., 2021), determining DS as the sample group for the current study was meaningful. Still, it should be highlighted that the age difference between the mothers participating in this study and their children with DS ranged between 25-35.5 years.

The current study aims to understand what kind of care mothers, who generally care for their children throughout their lives, want their children to receive in the future, as well as their expectations in the context of social policy. Accordingly, from a holistic perspective (as detailed in Chapter 4), semi-structured, in-depth interviews were conducted with mothers living with their children with DS in or near Istanbul, Turkey.

1.3 Outline of the chapters

Following the introductory chapter, Chapter 2 presents a general literature review to identify trends in the future care planning of parents with children with disabilities. In Chapter 3, outlines current disability-related policies in Turkey. Chapter 4 describes the methodology of the study, including the research design, the characteristics of participants, the pilot study, and the researcher's positionality. Chapter 5 offers a thematic analysis of the interviews conducted with mothers with children with DS to answer to the research questions addressed in this study. Finally, Chapter 6 discusses the findings of this study in terms of disability care-related policies in Turkey. In addition, the strengths and limitations of the study, and recommendations for future research are also mentioned.

CHAPTER 2

LITERATURE REVIEW

Considering the fact that PwD are having longer lives and may outlive their parents, future planning for PwD has emerged as one of the most important topics (Hodapp et al., 2017). Thus, the importance of understanding the experiences of families in long-term planning has also increased (Dillenburger & McKerr, 2011); moreover, families experience more significant stress without long-term planning, so engaging in future planning can offer numerous advantages (Lee & Burke, 2020). From the family caregivers' perspective, future plans can be described as several arrangements or ideas made by parents (Bigby, 1996); future planning approaches are closely tied to family circumstances (Prosser, 1997).

However, making the connection between the existence of a plan and its implementation is not always easy. Even parents who had several concrete plans envisaged that the implementation of their plans would not be take place before they passed away (Bigby, 1996). Most parents anticipated continuing to care for their children with a disability (McConkey et al., 2006). Considering the unique characteristics of children with intellectual disabilities, parents generally consider that family care provided by them is the gold standard concerning disability care (Prosser, 1997). Thus, parents' determination to continue care for as long as possible despite their increasing age is related to their view of themselves as the gold standard for care (Prosser, 1997). This viewpoint is probably related to the vulnerability and dependency of their children (Bibby, 2013; Hubert, 2006; Prosser, 1997), feeling indispensable in providing care and support for their child because of a lack of confidence in professional care environments (Bowey & McGlaughlin, 2007; Davys

et al., 2010; Iacono et al., 2016). This attitude suggests that mothers may either feel irreplaceable or struggle with passing on their caregiving responsibilities to others (Leane, 2020).

Still, future planning is important in all circumstances, where planning care options and supports leads to a positive influence for parents (Coyle et al., 2014; Heller & Caldwell, 2006; Lee & Burke, 2020). However, while advanced planning does not contradict the fact that parents may have choices and/or preferences about what they want to happen to their children with intellectual disabilities after relinquishing care (Walker & Hutchinson, 2018), parents may also tend not to plan for the future for a variety of reasons, even though they do not deny the importance of making such future plans for their children with intellectual disabilities (Bowey & McGlaughlin, 2007; Brennan et al., 2020; Engwall, 2017; Hole et al., 2013; Mengel et al., 1996; Pryce et al., 2017; Taggart et al., 2012; Walker & Hutchinson, 2018; Walker & Walker, 1998).

For example, the purpose of the Family & Individual Needs for Disability Support Community Report is to understand the experiences of families who provide support to a family member with intellectual or other developmental disabilities in the United States (Anderson et al., 2018). Approximately 7.3 million individuals with intellectual or other developmental disabilities reside in the United States, and more than half (53%) of those people with intellectual or other developmental disabilities live with their families (Larson et al., 2020). This means that families play an essential role in providing care to their family members with intellectual or other developmental disabilities. The study was first conducted in 2010 and updated in 2017; more than 3,000 people were included. In detail, more than half of the caregivers (54%) reported that they did not have a plan for their care-receiver's

future; however, those who reported having a plan were likely to be caregivers of PwID (51%). Those with low household incomes were less likely to report having a plan for the future (40%) than caregivers with higher household incomes (48%) (Anderson et al., 2018).

Family members who were not engaged in future planning indicated several factors that contributed to their lack of future planning. Parents may tend to refuse and avoid thinking and planning for the coming years due to practical and emotional issues (Taggart et al., 2012; Walker & Walker, 1998). For example, Hole et al. (2013) conclude that families shared their belief that family members would step up when the time came. Also, a sense of feeling burnt out, and formal and informal barriers, influenced their lack of engagement in future planning (Hole et al., 2013). In addition, Taggart et al. (2012) examined ageing family carers' preferences for future care for a relative with an intellectual disability and the support systems required to make such future plans. One parent from this study stated that ''not planning is just like a road accident; you always think it is not going to happen to you''. This statement also includes signs of denial about relinquishing the caring role and accepting their own death (Taggart et al., 2012). In addition, some participants clearly reported avoiding making plans as this was a very painful process (Taggart et al., 2012). Furthermore, parents who plan for the future would especially evaluate the situations for what happens to their children with intellectual disabilities after their own deaths; it requires them to face their own deaths (Walker & Hutchinson, 2018). Thus, due to the emotionally challenging nature of these issues, parents expressed a tendency to avoid engaging in future planning (Hole et al., 2013).

In addition, ageing parents who care for children with intellectual disabilities for most of their lives may not have the energy for planning their children's future

(Hole et al., 2013; Mengel et al., 1996). Moreover, when future planning is difficult because caregivers become older, this may also negatively affect the possibility of successful ageing of children with intellectual disabilities in the long run (Brennan et al., 2020). In a related study (Engwall, 2017), a parent stated that she was afraid of the coming years ahead and she was too old to consider how her child will be taken care of after her own death. This statement indicates that there may be multiple related reasons or excuses for not planning for the future such as parents may both refuse to think about the future and lack the energy to do so due to advancing age (Engwall, 2017). This situation may lead to a dilemma because, at the same time, they may not be planning for the future because their ageing does not affect their caregiving at the moment (Engwall, 2017); also, parents may be reluctant to make future plans while both parents are alive (Bowey & McGlaughlin, 2007).

Additionally, some parents who have a strong faith and/or religion might not always discern the need for future planning, especially if they have a more fatalistic approach (Pryce et al., 2017). They may also hope that the issues after their passing will somehow be resolved; these various reasons for not planning the future may stem from the parents' own family dynamics and characteristics, their own preferences or choices (Walker & Hutchinson, 2018).

Research shows that although families are aware of the vitality of future care planning for their children with intellectual disabilities, their plans are not concrete, or they do not plan future care because of various excuses or reasons as mentioned above. In families that planned for the future, the plans were often not comprehensive and concrete because they did not include diverse aspects of planning (Burke et al., 2018; Lee & Burke, 2020).

Furthermore, having a plan does not necessarily lessen parents' fears of the future care for children with intellectual disabilities (Taggart et al., 2012). For these reasons, although planning the future care of children with intellectual disabilities is seen as a duty that can be attributed to families and the moral obligation can be imposed on families by society regarding care (Prosser, 1997), such a vital and social issue should not be left solely to the initiative and possibilities of family members.

Still, some issues are emphasised by families when it comes to planning the future care of their children with intellectual disabilities. As detailed below, financial issues and residential and housing issues stand out as issues prioritised by families when it comes to planning the future care of their children with disabilities.

2.1 Financial issues

Participating families in related studies mentioned the importance of financial issues when considering the future care of their care receivers (Bigby, 1996; Coyle et al., 2014; Prosser, 1997; Taggart et al., 2012; Walker & Hutchinson, 2018). They have tried to ensure that their children with intellectual disabilities had sufficient money in order to minimize their concerns. Therefore, if possible, it is a common option to set aside a substantial amount of money to be used for future care needs (Bigby, 1996). Parents can provide an extra amount of their estate to their children with intellectual disabilities rather than giving the same amount to their typically developing other children (Coyle et al., 2014).

Also, for financial support, some families who have children with intellectual disabilities set up trusts that facilitate hold assets on their behalf; moreover, some parents also keep typically developing children involved in the trusts (Coyle et al., 2014). Future plans can include making a will (Walker & Hutchinson, 2018).

When parents make a will, they may give priority to their adult children with intellectual disabilities, and they will provide money or property directly to the adult children with intellectual disabilities (Prosser, 1997). Families tend to draw up wills for all or part of the estate for adult children with intellectual disabilities; thus, they can name their adult children with intellectual disabilities as beneficiaries (Bigby, 1996). However, since the care receiver can be an adult child with intellectual disabilities, sometimes these plans may require the appointment of a family member as a trustee (Bigby, 1996). This trustee generally is chosen from among the other siblings, if there is one, and it is hoped or given an undertaking that a significant portion of the estate will be used for the benefit of the sibling with the intellectual disability (Bigby, 1996; Prosser, 1997).

Caregivers express concerns about financial issues, both for themselves and for the individuals they care for. This underscores the necessity for services such as healthcare, transportation, and housing to be affordable and of high quality (Akkan, 2010; Altuntaş & Atasü-Topçuoğlu, 2016). Achieving this requires support from both communities and governments to ensure equitable access for caregivers and those they care for (Hart & Neil, 2021).

2.2 Residential and housing issues

Besides financial issues, the issue of where children with intellectual disabilities, who currently live with their caring parents, will live once their parents are no longer able to care for them may be the first long-term concern in future care planning. There is no consensus on where to stay or where it would be better for children with intellectual disabilities to stay after their parents' death or when their parents become ill. Although there is, no single correct answer regarding residential and housing

choices, for most families of children with intellectual disabilities participating in similar studies, planning for future housing conditions is one of the vital issues (Bigby, 1996; Garnham et al., 2019; Hewitt et al., 2013; McCausland et al., 2019; McConkey et al., 2006; Taggart et al., 2012; Walker & Hutchinson, 2019). Accordingly, some families of adult children with intellectual disabilities have various accommodation plans for the future because, in the opposite scenario, adult children with intellectual disabilities may encounter various accommodation problems, ranging from being unable to live in safe, accessible and affordable housing in a sustainable manner to homelessness. In other words, without future planning, there is a greater risk for negative outcomes, such as inappropriate living conditions (Hewitt et al., 2013).

Supported accommodation (defined as community-based accommodation for PwD) can be a choice for parents (Walker & Hutchinson, 2019). Parents whose children are already living in supported accommodation consider it as part of future planning for their children in case of their own death. Therefore, it appears that they do not consider other alternatives. However, they also state that by not considering alternatives to these institutions, they may have exaggerated expectations of them (Walker & Hutchinson, 2019).

Moreover, families noted that service providers did not develop any dialogue concerning the post-parental period of their children with intellectual disabilities' lives (Walker & Hutchinson, 2019). Also, some families whose children were not currently in supported accommodation were involved in future planning through planning the transition to supported accommodation for their children (Bigby, 1996). Moving to a residential facility with other PwIDs may be another option. Residential care facilities, also called group homes, are private facilities for those requiring

specialist care. Some facilities primarily serve adults under the age of 60, and others primarily serve adults aged 60 and over (National Institute on Aging, 2019).

Residents can be independent in their private rooms while also having opportunities to socialize in shared communal areas. Although families have expressed concerns about the quality of care their children would receive at such facilities, this is preferred when parents do not want to burden other children with the caring role in general (Bigby, 1996; Taggart et al., 2012). However, although in a study, the family of the child with a disability preferred to transition to full-time residential care (a type of publicly-funded care or service to the public), this option was not available because of a lack of capacity (McCausland et al., 2019). For example, although a family wanted their child to be in a group home, they stated that at the time, there was no such facility in their town (McConkey et al., 2006). Also, because of a lack of capacity, placing the child's name on a waiting list for residential services is another common step in future planning (Bigby, 1996).

Moreover, nursing homes were another option. This option is particularly for older people; however, some families whose children have a high possibility of suffering from some health issues, such as dementia, also consider nursing homes for the future in the long run (McConkey et al., 2006). Parents' planning preferences concerning housing may differ based on the child's needs, the type and amount of support needed, and, of course, families' and institutions' opportunities. Regardless, care receivers and caregivers should jointly design the housing conditions for the post-parental care period (Garnham et al., 2019).

However, families who choose accommodations in institutions in the community for their children expressed concerns about the possibility of abuse or misconduct (McConkey et al., 2006). Moreover, the quality and sustainability of

privately funded services were highlighted as remarkable concerns (McConkey et al., 2006).

The most commonly chosen institutionalized options are often emphasized; however, some families prefer to use their own resources for accommodation planning. For example, it was stated that despite the presence of a sibling, the relationship between the sibling and the family was not close, and, therefore, another accommodation plan was devised, which did not include the sibling (Bigby, 1996). According to this planning, the parent planned to build a house on a vacant lot in a retirement complex. Afterwards, the parent agreed that in case the child would receive care there, the built house would be donated to relevant foundations (Bigby, 1996).

The option for children to live with another family has seldom been chosen (McConkey et al., 2006); however, if planning to live outside the institution and with a family, the first choice is mostly siblings (Bigby, 1996). Even when families did not discuss future plans for their adult children with intellectual disabilities with other siblings with intellectual disabilities, some parents assumed that other siblings would care for their siblings with intellectual disabilities (Heller & Caldwell, 2006; Orsmond & Seltzer, 2000). Siblings may recognise this implicit understanding concerning their parents' expectations; for example, a sister stated that her mother did not need to discuss her future planning for her sibling with an intellectual disability (Bigby, 1996; Heller & Caldwell, 2006).

On the other hand, this is not a generalizable case and cannot be considered the default. However, some parents explicitly willed that other children should take care of their siblings with intellectual disabilities when they died, and some siblings accepted this wish (Bigby, 1996). Sometimes, they might take on this caregiving role

unwillingly (Pryce et al., 2017). Interestingly, parents who were foster parents of their children with intellectual disabilities were adamant that they would not include their other children in siblings' future care (Walker & Hutchinson, 2018).

Although the critical significance of residential and housing issues for children with intellectual disabilities in the future is considered, families had concrete plans mostly related to financial arrangements rather than housing conditions while planning the future (Heller & Caldwell, 2006; Prosser, 1997). One of the most valid reasons for this tendency is the determination and willingness of parents to provide home-based care for their children for extended periods as long as possible (McConkey et al, 2006; Prosser, 1997).

Still, although families have difficulty in making future care plans for their children with disabilities for various reasons, financial issues and housing conditions stand out as the significant issues that come to the fore when families cannot continue to care for their children with a disability.

2.3 The special importance of future care planning for people with Down syndrome

DS is the most frequently occurring chromosomal disorder and the leading cause of intellectual and developmental delay in the world (World Health Organization [WHO], 2000). John Langdon Down linked a population with distinct physical characteristics to decreased intellectual ability (Down, 1866), and then, Jerome Lejeune discovered DS is a genetic disorder whereby an individual has three copies of chromosome 21 (Gardiner & Davisson, 2000; Hattori et al., 2000), instead of two (Lejeune, 1959).

About 95% of people with DS have the classic type of Trisomy 21. In this type of DS, there are three separate copies of chromosome 21 in each cell in the body

instead of the typical two copies. Also, there are very rare forms of DS (less than 6%) called Translocation DS or Mosaic DS, in which not all of the chromosome is triplicated or not all cells of the body carry the extra chromosome (Flores-Ramírez et al., 2015). In the case of hereditary Translocation DS, an extra chromosome 21 is inherited from one of the parents. Translocation DS accounts for a small percentage of people with DS, approximately 3%. In this type, part or all of the 21st chromosome is located or attached to another chromosome rather than as a separate 21st chromosome (a piece of chromosome 21 is located or attached to one of the mother's or father's other chromosomes). Also, approximately 2% of people with DS have Mosaic DS, which means mosaic mixture or combination. Some of the cells of children with Mosaic DS have three copies of chromosome 21, but others typically have two copies of chromosome 21. Children with Mosaic DS may have the same characteristics as other children with DS; however, fewer features of DS may be present due to the presence of cells containing a typical number of chromosomes. Most of the time, the differences between types often cannot be detected through physical features and behaviors alone, thus requiring chromosomal testing (Turkish Fetal Medicine and Perinatology Association, 2020).

DS is not associated with race, nationality, socioeconomic status, religion, or any actions taken by the mother or father during pregnancy (Global Down Syndrome Foundation, 2018). The exact cause of DS is unknown. During egg formation, a phenomenon called nondisjunction occurs, where the two copies of chromosome 21 do not split as they should. However, the specific cause of this nondisjunction is not known (Global Down Syndrome Foundation, 2018). It is claimed that the likelihood of having a baby with DS rises as the mother's age increases because the probability of faulty chromosome division is higher in older eggs.

Nonetheless, roughly half of babies with DS are born to mothers under 35 years old due to the fact that more young women are opting to have children (Acar et al., 2014; Global Down Syndrome Foundation, 2018). Also, being a carrier of a genetic translocation for DS increases the possibility of having a baby with DS because parents can pass the genetic translocation of DS to their children. Medical geneticists can help parents assess the possibility of having a second child with DS. Additionally, couples who have a child with DS and who have a balanced translocation are more likely to have another child with DS (Turkish Fetal Medicine and Perinatology Association, 2020).

Prenatal screening tests are tests that determine the likelihood of having a baby with DS. These tests do not inform whether the fetus has DS, only the probability (National Institutes of Health, 2023). Screening tests include first-trimester screening tests, second-trimester screening tests (triple screening tests, quadruple screening tests), and extracellular DNA tests (National Institutes of Health, 2023).

As mentioned, prenatal screening tests are only probabilistic, whereas diagnostic tests provide a definitive diagnosis with 100% accuracy. Diagnostic tests include chorionic villus sampling, amniocentesis, cordocentesis and postnatal diagnosis. Chorionic villus sampling, performed between the 10th and 13th weeks of pregnancy, determines the chromosome structure in cells obtained from tissue samples taken from the organ called the placenta that feeds the baby. Amniocentesis is performed between the 15th and 20th weeks of pregnancy and is used to determine the chromosome structure in the cells in the amniotic fluid around the fetus.

Cordocentesis is performed between 18 to 22 weeks of pregnancy and detects the chromosome structure in lymphocyte cells in the blood sample taken from the

baby's umbilical cord. Finally, diagnosis in the postnatal period is made by taking a blood sample from the baby and performing chromosome analysis to make a diagnosis in the presence of findings such as loose muscle in the newborn baby, a single palm line on the hand, a flattened facial profile, upward-slanted eyes, and a flattened nasal root (National Institutes of Health, 2023).

Although the exact reason behind of DS is unknown, it can be detected before the child is born and health problems that may occur with DS can be treated. The physical characteristics and medical problems associated with DS can vary widely from child to child; some children need a lot of medical support, while others can survive with less support (Turkish Fetal Medicine and Perinatology Association, 2020). Also, people with DS may have various health problems such as heart defects, stomach and intestinal issues, immune system disorders, endocrine problems, obesity, spine problems, leukemia, dementia, dental problems, ear infections and hearing and vision problems (Baumer et al., 2023; Heinke et al., 2021; Turkish Fetal Medicine and Perinatology Association, 2020).

Early intervention is crucial for babies with DS; implementing suitable physical and speech therapies during the initial five years can significantly impact the child's physical and intellectual progress. Although people with DS look similar and behave similarly, each person has different abilities (Turkish Fetal Medicine and Perinatology Association, 2020).

It is known that the life expectancy of people with DS has increased compared to the past (Bittles & Glasson, 2004; Bittles et al., 2007; Carter & Jancar, 1983; Covelli et al., 2016; Glasson et al., 2002; Motegi et al., 2021; Presson et al., 2013). However, in comparison to the general population, people with DS start to age prematurely (Roth et al., 1996); indeed, people with DS tend to exhibit health-

related issues at around age 45, which typically emerge in the general population around the age of 70 (Coppus et al., 2008). In other words, people with DS are more likely to develop dementia than other PwD; age-specific prevalence rates of Alzheimer's disease were similar but 30-40 years earlier in life for people with DS (Furniss et al., 2012; Holland et al., 1998).

Planning for the future is important for everyone. However, plans are especially essential for people with DS to ensure the continuity of many achievements from the previous years, both at life skills and health conditions levels. The ageing of people with DS requires attention to planning their future; in order to make better plans, it is necessary to make decisions before an emergency occurs (Covelli, 2018). The ageing of people with DS has important implications, especially for the time in which their current carers, that is, their parents, are no longer alive.

Future planning was based on age and/or the presence of family members; thus, in the case of no family members, people with DS could be institutionalized, and/or, in most cases, their sisters/brothers had to manage their future due to the parents no longer being alive (Furniss et al., 2012). Furthermore, typically developing siblings were concerned about being unable to care for their siblings with DS and felt a strong sense of responsibility for them (Furniss et al., 2012). People with DS who live at home may retain more independence over time than people with DS who live in institutional care; indeed, health professionals reported a reduction in independence in people with DS after their process of institutionalization (Covelli et al., 2016).

Covelli et al. (2016) investigated family members' and health professionals' perceptions of the daily lives of people with DS to understand which aspects are important in better planning their future from a biopsychosocial perspective. The

most pertinent aspects for managing the daily lives of people with DS in their later years were reported to be the interaction between health and environment, along with the maintenance of continuity in daily routines. In addition, the health of people with DS tends to suddenly deteriorate when they start to age, and thus, it is important to monitor it (Covelli et al., 2016). However, in order to better plan their current and future lives, not only their health conditions but also all aspects that characterize their existence should be considered from a biopsychosocial perspective (Covelli et al., 2018). Examining future planning and social policy expectations of mothers who have children with DS can facilitate to consideration of both the health conditions and all aspects characterizing their existence from a biopsychosocial perspective.

In this chapter, the main literature when it comes to future care planning for children with disabilities were highlighted, and the importance of future care planning specifically for people with DS is underlined. In the following section, policies regarding PwD in Turkey are mentioned.

CHAPTER 3

CURRENT POLICIES RELATED TO DISABILITY IN TURKEY

In the current study, which aims to explore future care planning and social policy expectations of mothers with children with DS, examining current social policies related to PwD in Turkey is vital. In this way, it would be possible to understand existing related social policy schemes and highlight the shortcomings while exploring the social policy expectations of families.

Social policy schemes refer to various programs, initiatives, and measures implemented by governments and organizations to address social issues and promote the well-being of individuals and communities. These schemes aim to provide assistance, support, and protection to vulnerable groups, mitigate inequality, and ensure access to essential services and resources (Drake, 2018).

How states respond to care needs in society shapes the distribution of responsibilities and expenditures among the state, market, and family (Daly & Rake, 2003). As Marshall (2008) underlines, citizenship status could be employed in order to ease the inequality of the social class system and aspire for equality for all through social policies (Marshall, 2008). However, the liberal understanding of citizenship is based on the assumption of the self-sufficient individual; self-sufficiency is considered identical to autonomy. According to this understanding, dependent individuals are positioned as individuals who have lost their autonomy and as needy people who cannot make decisions about themselves (Tronto, 1994). In the liberal citizenship paradigm, dependency is perceived as a situation that can be stigmatized in the public sphere, should be ashamed and should be overcome. In this case, the dependency is rendered as invisible as possible in the public domain (Sennett, 2003).

The current government in Turkey has economically liberal and socially conservative characteristics. The government emphasizes the importance of the family to achieve social solidarity within the domains of social care and social assistance (Buğra, 2008). Since the family is seen as the basic unit of society and is expected to play a significant role in the upbringing and care of children, people with disabilities (PwD), and elderly family members in general, this perspective also lays the groundwork for consolidating patriarchal values (Buğra & Keyder, 2006).

In Turkey, the Justice and Development Party (Adalet ve Kalkınma Partisi [AKP] in Turkish) , which has been in power since 2002, inherited the socio-economic conditions for PwD that were clearly worse than those of the general population, and since then, the AKP has brought PwD to the forefront of social policy.

However, due to AKP's policy approach, developments in the domain of social policies concerning disability trace the main features of the existing family-based welfare regime of Turkey and indeed strengthen these characteristics. According to the AKP discourse, intervention in market distribution is not justified when the topic is care since the ''holy'' Turkish family take care of its members with disabilities and would not let economic marginalization of them (Buğra, 2008). Thus, the AKP strengthened both the conservative and liberal residual flavors of Turkey's welfare regime by limiting eligibility to the most disadvantaged rather than introducing universal provision and by supporting family solidarity rather than independent living (Buğra, 2008; Yılmaz, 2010; Yılmaz, 2011). Indeed, the AKP policy discourse also consistently highlights that families should provide this care in the family rather than relying on outside institutions, and this approach is reflected in policies.

Institutional care is seen as a last option, and family care is emphasized in political discourse. For this reason, home-based care and institutional disability care are distinguished while examining the relevant policies in Turkey.

Also, since care is considered a type of action that includes everything done to improve life in the best way (Fisher & Tronto, 1990) in this current study, it would be meaningful to mention together the services and cash transfers that may be directly or indirectly related to the care of the PwD. In this research, Turkey's disability care policies are analyzed by categorizing them as institutional or home-based care and by disaggregating whether they involve cash transfers and/or service provision. As Figure 1[1] shows, policies that may be related to disability care are mainly provided by cash transfers and/or service delivery in institutions and/or at home, and there may be intersections in Turkey.

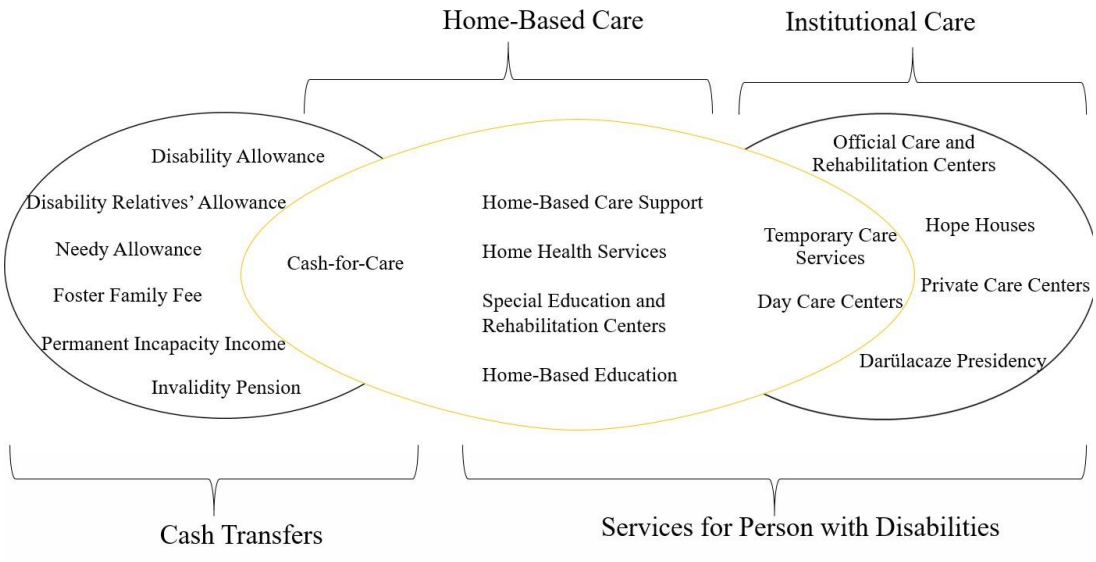


Figure 1. Current schemes related to disability and disability care in Turkey

[1] Figure 1 was categorized and shaped by the researcher as a result of the realization that the social assistance and services in Turkey, which are mentioned in the following section, basically differentiate and intersect as home-based care, institutional care, cash transfers, and disabled services.

Cash transfers, home-based care, and institutional care issues related to disability care also came to the fore in the qualitative analysis section of the current study. For this reason, it is essential to show the current policies regarding disability care in Turkey within the scope of these headings with a figure to provide a facilitating framework.

Cash transfers as social assistance can be essential to disability care policies because they help financially support PwD and their caregivers. Cash transfers can help offset the cost of specifically disability-related expenses and also help improve the overall quality of life for PwD and their caregivers. In Turkey, there are some cash transfers for PwD; however, only one of them is directly related to care for PwD, which is cash-for-care (ASHB, 2023b).

Minister of Family and Social Services of the period reiterates in her statements that cash-for-care prioritizes the care of PwD at home to preserve family integrity. In 2024, the amount of cash-for-care was set at 7,608 Turkish Liras, and 558,000 caregivers receive cash-for-care. As of February 2024, the total cost of cash-for-care, attributed to preserving and strengthening family unity, was approximately 4.2 billion Turkish Liras. Since the scheme started (in 2007), 113.4 billion Turkish Liras have been paid (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2023a).

Considering the exchange rate as of 02.03.2024, 7,608 Turkish Liras corresponds to 223.56 euros (1 Euro equals 34.03 Turkish Liras) and 242.67 USD (1 USD equals 31.35) (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2024a). On the other hand, the minimum wage is the wage for a worker to meet his or her basic needs. The

net minimum wage in Turkey 2024 is 17,002 TL, which is approximately 542.30 USD, 499.61 Euro nowadays (03 March, 2024) (Ministry of Labor and Social Security [Çalışma ve Sosyal Güvenlik Bakanlığı], 2024). As highlighted, monthly cash-for-care payments amount corresponds to 242.67 USD and 223.56 euros (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2024a) Considering the minimum amounts regulated to meet basic needs, the amounts determined for payments to the PwD do not seem to make a livable life possible. Moreover, it is known that the minimum wage determined in Turkey is well below the minimum wages determined by the countries in the European Union (Eurofound, 2024); similarly, the minimum wage in the United States was an average monthly minimum wage of 1,160 USD (Statista, 2023).

Under these conditions, it is clear that the current cash-for-care amounts cannot make a livable life possible, considering the purchasing power and inflation effects in Turkey (BİANET, 2023).

Mainly, other cash transfer programs can be listed as disability allowance, disability relatives' allowance, needy allowance, and foster family care fee (ASHB, 2023b). In detail, according to Law No. 2022, 5 types of allowance are granted, these are elderly allowance, disability allowance between 40-69%, disability allowance of 70% and above, disability relatives' allowance (disability allowance under the age of 18), and silicosis allowance (ASHB, 2023c). Disability allowances are payments granted to citizens with disabilities over the age of 18 who have a disability rate of at least 40% or more, who are not subject to any of the social security institutions established by law, and whose neediness has been documented. Also, PwD with disabilities of a percentage of 70% or more receive higher payment than those with a

disability percentage of 40% - 69%; the disability percentage is one of the distinguishing criteria. Moreover, in accordance with the same law, a disability relatives' allowance is a cash transfer given to caregivers who care for children with disabilities. It is usually given to the family caregiver who resides in the same household and takes care of a PwD who is under 18; similarly, relatives of PwD should also not have any kinds of social security. Care receivers should be under the age of 18 and with at least a mild level of special needs[2] or those with disabilities of a percentage of 40% or more (ASHB, 2023b).

Since February 20, 2019, the processes and the content of the medical disability report have changed and the reports to be given to children and adults have been separated. Thus, this change brought a new approach to children's evaluations and the reporting process. According to the new regulation, a special needs report is issued for children (ASHB, 2023a). Since February 20, 2019, the disability status of children is evaluated with Special Needs Evaluation Report for Children (ÇÖZGER) issued by authorized hospitals. Children under the age of 18 are covered by this regulation. In the ÇÖZGER Regulation, the special needs levels of children are determined without specifying the concept or rate of disability (Republic of Türkiye Ministry of Health [Türkiye Cumhuriyeti Sağlık Bakanlığı], 2023). However, medical disability reports stating the disability rate despite being under 18 years of age may refer to indefinite disability reports received before 2019, before ÇÖZGER came into force.

[2] Within the scope of the current study, individuals are generally expressed with "people first language" since it provides a language that is not imbued with stereotypes and preconceived ideas about the individual who happens to be differently-abled to society in general, such as people with disabilities (PwD), people with intellectual disabilities (PwID), people with Down syndrome (DS). However, in cases where people are under 18, both the expression special needs are used in accordance with the ÇÖZGER approach and children with disabilities in accordance with "people first language approach" are used.

In 2024, those whose disability rate is 40-69% and those disability relatives receive an allowance of 2,797 Turkish Liras, and those whose disability rate is 70% and above receive a disability allowance of 4,196.70 Turkish Liras. In February 2024, 6.3 billion Turkish Liras were paid, including approximately 3.5 billion Turkish Liras for elderly allowance and approximately 2.8 billion Turkish Liras for disability allowance (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli Ve Yaşlı Hizmetleri Genel Müdürlüğü], 2024b). Income criteria are the most important determinant of receiving these allowances, and the evaluation of neediness regarding income is controversial since it is based on the number of people in the households.

Also, the General Directorate of Foundations, affiliated with the Ministry of Culture and Tourism, pay the needy allowance as a cash transfer. The needy allowance is given to a person in need who does not receive social security, does not have any income or allowance (those who receive cash-for-care or Law No. 2022 allowance cannot apply) and those with a disability percentage 40% or more. In addition, the payment can be conditional on not possessing income-generating movable or immovable property, or if the average monthly income derived from such properties does not exceed the specified needy allowance as determined by this regulation. (Republic of Turkey General Directorate of Foundations [Türkiye Cumhuriyeti Vakıflar Genel Müdürlüğü] [VGM], (2023).

Besides, since children with disabilities often face unique challenges and have specific needs that may not be adequately addressed in general policies, it is crucial to develop separate policies for children with disabilities. Turkey signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on March 30, 2007. The signing of this convention marked Turkey's commitment to

recognizing and protecting the rights of PwD. In the UNCRPD, it has been accepted that the state parties should undertake every effort to provide alternative care to a child with a disability whose immediate family is unable to care for the child with disabilities. This care can be provided either by the wider or extended family or, failing that, within the community in a family setting (United Nations [UN], 2006).

In Turkey, The General Directorate of Child Services, which is also affiliated with the Ministry of Family and Social Services, deals with children who cannot benefit from their biological parents' care for various reasons and under government protection; this also applies to children with disabilities. In Turkey, children with disabilities are protected under the laws and regulations that pertain to the protection of children in general, as well as specific laws and regulations that address the rights of children with disabilities (ASHB, 2023d). Children under protection in Turkey benefit from institutional care and family-based care models. Children with disabilities under the age of 18 can receive care in institutions affiliated with the General Directorate of Child Services. Also, the foster family is a family-based care model in which children who cannot be cared for a while with their biological family for various reasons share the responsibility of education, care, and upbringing in a family environment for a short or long-term, under the control of the government (Alternative Care, 2022). For each child they care for, foster families are paid a monthly fee for their care, education, and upbringing expenses. More than 10% of children placed in foster families are children with disabilities. For children with special difficulties or needs, or with disabilities, the monthly foster family care fee is increased by 50 percent; in practice, some foster families take care of children with a 100% disability rate (ASHB, 2023e).

Disability allowance, disability relatives' allowance, needy allowance, and foster family care fee for children with disabilities are examples of cash transfers in Turkey that may be used to care for PwD (ASHB, 2023b).

Moreover, there are also cash-for-care schemes, an example of a cash transfer that is given to caregivers of PwD and directly connects care and disability. This scheme aims to support PwD or chronic illnesses to live in their own homes and communities rather than having to live in institutions or residential care facilities.

Accordingly, in order to support the home-based care of PwD in need of care, a cash- for-care scheme was instituted in 2007 (ASHB, 2023f). A cash-for-care stipend is paid to people who assume care for PwD at home, which means not the support given to the PwD themselves but to third parties such as relatives and guardians who care for them. A cash-for-care is given to PwD with a disability percentage of 50% or more and who have the statement "Severely Disabled"/Fully Dependent" in the medical disability report (ASHB, 2021a). Significantly, household income status is considered; in this context, care is taken to ensure that the per capita income in the household is below 2/3 of the net minimum wage (ASHB, 2021a). While the number of people benefiting from a cash-for-care scheme was 28,583 in 2007, this number increased by 19.5 times and reached 559,900 in 2022 (ASHB, 2021b).

Also, if the families of PwD who are cared for at home but cannot benefit from cash-for-care schemes and/or day/boarding institution care services need support in caring for PwD, home-based care support service is provided. It is the care service provided by the caregiver staff working in the official care and rehabilitation centers to the residence address of PwD in need of care on the days and times determined at home (ASHB, 2006). In line with the individual care plan to be

prepared by the central evaluation board, care service is provided by the caregiver professional under the supervision and guidance of the home-based care service unit (ASHB, 2006). Also, patients with disabilities who are unable to go to the hospital from home due to their disability and who want to receive home-based health care services can request home health services by applying to their family physicians or by calling the national call center within the Ministry of Health (Republic of Turkey Ministry of Health [Türkiye Cumhuriyeti Sağlık Bakanlığı], 2019). It is possible to provide an examination, analysis, treatment, medical care and rehabilitation services in the home environment, within the framework of the diagnosis and planned treatment, for those who are found suitable to receive home health services (Republic of Turkey Ministry of Health [Türkiye Cumhuriyeti Sağlık Bakanlığı], 2019).

Besides cash-for-care and home-based care support to ensure the continuity of home-based care for PwD, there are also institutional care services under the General Directorate of Services for Persons with Disabilities and the Elderly.

Boarding and day-care services are provided to PwD who need care in official care and private care centers (ASHB, 2023a). Official Care and Rehabilitation Centers are centers where PwD are placed by age, gender and disability, and care and rehabilitation services are provided. In receiving care services from Official Boarding Care and Rehabilitation Centers, a medical disability report is required for PwD who receives service. Individuals who submit a medical disability report can receive care from these centers free of charge, regardless of whether they have any income or not (ASHB, 2023a). Furthermore, Hope Houses are additional units put into service to enable PwD who receive care in official care and rehabilitation centers to participate in social life and live in the community (ASHB, 2016). PwD who receive care in official care centers can be

directed to Hope Houses in line with the consideration report of the professionals. Hope Houses, which are home-type social care services, aims to change the perception from institutional care to the community-based care service model. The first Hope Houses were put into service in the province of İzmir in 2008, which have reached 149 currently. They are preferably opened in an apartment or a detached residence in the city center and are residential applications where 2 to 6 PwD stay together. PwD living in these facilities consist of those who can do their own self-care and go to school or work (ASHB, 2016). It is stated that 654 PwD are offered living conditions in a home environment in 149 Hope Houses (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2023b). If the conditions of the house where the person with a disability who applies with a request to be taken into care meet the determined standards, the house where they stay without leaving their home can be turned into a Hope House (ASHB, 2016). Also, if PwD who are in institutional care have their own houses, their requests can be evaluated, and their houses can be converted into Hope House. Moreover, PwD can stay in the Hope Houses with a typically developing relative who is also their legal representative. However, in this case, he/she covers his/her own expenses and must pay a regular contribution to Hope Houses (ASHB, 2016).

Within the scope of the older PwD care services currently carried out in Turkey, there are nursing homes, care and rehabilitation centers and elderly living homes as institutional, residential care services. In addition, residential elderly care institutions belonging to private and related non-governmental organizations can also provide services with similar names. In institutional care for elder PwD, disability status should be taken into account, as well as old age characteristics. Despite the

differences in the names of these institutions that provide residential care services for older PwD, the main difference is that independent older adults who can meet their own needs are served in nursing homes, while services are provided to older adults who require special and inpatient care in the official care and rehabilitation centers (Karakuş, 2018). However, in both types of institutions, care services can also be provided to the elderly from the other elderly group, albeit in small numbers. For example, the fact that the independent elderly, who can meet their own needs, require special care over time may make it necessary for these elderly people to continue to stay in the same institution (Karakuş, 2018).

In addition, PwD in need of care can receive boarding or day-care services in private care centers opened by real persons or private legal personalities and supervised by the Provincial Directorates of Family and Social Services (ASHB, 2023a). Private care centers, which were initiated in 2007 in order to provide care services to PwD who need institutional care, benefit PwD in accordance with the criteria in the relevant legislation (ASHB, 2021a). When in 2007, 351 PwD received care services in 10 private care centers, and 26,491 people benefited from boarding care services in 304 private care centers as of September 2022 (ASHB, 2022a). In order to receive special care services in the status of disabled, and someone who is covered by the Ministry, it should be stated in the report of the Disabled Medical Board to be a fully dependent PwD. The sum of all revenues should be less than 2/3 of the monthly net minimum wage of the household's average monthly income per capita. In this status, all expenses of PwD placed in the center are covered by the relevant ministry (ASHB, 2023a).

Additionally, the Ministry of Family and Social Services has the Darülaceze Presidency, a public institution with a special budget and legal personality. It accepts

people with orthopedical disabilities over the age of 18 and elderly who are unable to perform their self-care and skills but have economic competence, and all clothing, shelter, food, health and care needs of the residents are met by the institution (Darülaceze Presidency, 2023). However, the institution has moved away from providing an inclusive service to all disability groups by adding the condition of "being in good intellectual and mental health" to the admission conditions.

Institutional care may have risks for the PwD, such as sharing the same environment only with other people in need of care, limited interaction with the outside, and being isolated from social life and relationships (Altuntaş & Atasü-Topçuoğlu, 2016). Due to the cost of institutional care and the negative effects it may have on the psychology of the caregiver, there is a trend towards the dissemination of community-based care services in the world today (Altuntaş & Atasü-Topçuoğlu, 2016).

In Turkey, there are institutional care services that can support the continuity of home-based care in accordance with the family-based care discourse of the Ministry. In addition, when the content of these services is evaluated, they can be considered examples of respite care for both care receivers and caregivers; "Temporary Care Services" and "Day Care Centers" are examples of these (ASHB, 2021a). In addition to boarding care services, PwD who are cared for by their families under normal conditions can be provided with temporary and guest boarding care in official care centers, if needed (ASHB, 2021a).

Temporary Guest Care Service is a temporary care model offered in existing boarding institutions for PwD. Especially families of PwD receiving home-based care support can benefit in case they need to temporarily leave their family member with disabilities (ASHB, 2023a). PwD admitted to the center within the scope of the

temporary care model benefit from all the care services offered to other PwD receiving service at the center. Based on the petition of the PwD or his/her legal representative, medical disability report, the service contract and the evaluation report of a professional, the PwD can be placed in the official care center as a temporary guest (ASHB, 2023a). According to this, PwD can stay in the centers temporarily and as a guest for a maximum of thirty days a year (ASHB, 2021a). In other words, this service is limited to a certain period of time, preventing families from leaving their family members under their care for an indefinite period of institutional care and preventing them from staying in the institution's care permanently.

Day-care centers provide services for PwD receiving home-based care to continue to receive care without leaving their family environment (ASHB, 2022b). These centers are defined as day-care service model offered as full or part-time or sessional service to ensure that family members who care for the PwD can take time for themselves and participate in social life during the day and to provide care for PwD without being separated from their family and their environment (ASHB, 2022b; ASHB 2023a).

In the centers providing day-care services, educational, social, cultural and sports activities are carried out to meet the self-care needs of PwD as well as to ensure their participation in social life (ASHB, 2006). It is emphasized that the day-care service model is also crucial in reducing the need for long-term residential care services for PwD who live in their own homes with families (ASHB, 2019). Day-care centers, which aim to act as a bridge between home-based care and institutional care, are believed to greatly support the preservation of the traditional family structure (Mersin Governorship, 2022). While 459 individuals benefited from day-

care services in 6 day-care centers in 2017, in 2021, 1,233 PwD were served in 129 day-care centers (ASHB, 2021a). By the end of 2023, day care service centers have increased to 136 (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2023c). Also, in September 2022, 1,467 people benefited from these centers, and the Ministry aims to increase the number of PwD receiving services through the centers (ASHB, 2021a).

In addition, there are Special Education and Rehabilitation Centers, which are institutions that provide support education services to individuals with special education needs (General Directorate of Special Education and Guidance Services [Özel Eğitim ve Rehberlik Hizmetleri Genel Müdürlüğü], 2020). Special education and rehabilitation centers aim to prepare with an approach centered on students with disabilities to reduce mental, physical, auditory, visual, social, emotional, language and speech difficulties and behavioral problems to improve their self-care, independent living and functional academic skills, to enable them to become self-sufficient and adapt to society (Republic of Turkey Ministry of National Education [Milli Eğitim Bakanlığı] [MEB], 2018). Also, home education/home-schooling services can be provided for students with special education needs at the age of compulsory education. Students can benefit from this in cases where they cannot benefit from formal education institutions for at least twelve weeks due to health problems or in case of a risk to their health if they benefit from formal education.

While determining the courses to be taught to students following the special education program, planning considers the students' educational needs and characteristics (Republic of Turkey Ministry of National Education [Milli Eğitim Bakanlığı] [MEB], 2018). The hours of these education services are limited, and their adequacy is controvertible.

In the following section of this chapter, other schemes depending on several determinants such as age, disability and occupation were highlighted. There are other schemes that can be indirectly related to disability care in Turkey. In the event of the death of an insured employee, the surviving spouse, child, mother and father of the insured may receive a pension, expressed as a survivor's pension, as long as they meet the appropriate conditions.

The disability rate of those who benefit from the social security of their deceased parents is essential. Children whose mothers or fathers have died and who are found to be 60% or more disabled are given a pension at 25% of their deceased mother or father's pension, calculated by Law No. 5510. Children covered by this article can benefit from this pension for life; age, student qualification and being single are not required for children with disabilities. Those who want to benefit from this allowance must have a medical disability report at a rate of more than 60%, must not receive salaries such as disability allowance and old-age allowance specified in Law No. 2022, and must not be insured (Turkish Down Syndrome Association, 2023). Age, gender and educational status are the determining factors in children with disability below 60%. Although the age limit for men differs according to the education level, 25% is paid monthly for men under the age of 25. For women, regardless of their age, 25% of the monthly salary is paid to each unmarried, married but divorced or widowed girl or women (Turkish Down Syndrome Association, 2023). Additionally, with an additional article introduced in the Social Insurance and General Health Insurance Law No. 5510 in 2008, the possibility of retiring earlier than the standard period is allowed for a female insured who cares for a child with severely disability, regardless of whether she is the biological mother or not (Social Security Institution, 2006). Moreover, it is mentioned that in the current regulation,

the mother's early retirement requirement depends on the child's severe disability.

However, with the implementation of ÇÖZGER, there is no statement indicating whether children under the age of 18 are severely disabled or not. In this context, a regulation should be made to cover ÇÖZGER for mothers with children under 18 to meet the retirement requirement (Grand National Assembly of Turkey [Türkiye Büyük Millet Meclisi], 2020). Also, the absence of a special regulation for fathers is also an indication of the fact that women are appointed as caregivers on the basis of legal regulations.

In addition, within the scope of the Social Insurance and General Health Insurance Law No. 5510, permanent incapacity income is provided under the work accident or occupational disease insurance, and invalidity pension. When the earning power in the profession has decreased by at least 10% due to illness or disability as a result of a work accident or occupational disease, and it is determined that someone else is in need of constant care; in that case, the person is entitled to permanent incapacity income (Social Security Institution, 2006). For the invalidity pension, it must be determined by the Institution's Health Board that at least 60% of the working power or earning power in the profession has been lost (Social Security Institution, 2006). On the other hand, since the provisions of Law No. 5510 regarding an invalidity pension are related to illnesses and disabilities that occur after the date the insured starts working, and DS, autism and other developmental disorders are considered congenital diseases, they are not evaluated within this scope (Grand National Assembly of Turkey [Türkiye Büyük Millet Meclisi], 2020). While an invalidity pension is a right provided by long-term insurance branches, permanent incapacity income is provided by short-term insurance branches (Social Security Institution, 2006).

Another concept that can be associated with Social Insurance and General Health Insurance Law No. 5510 and disability is the issue of "care insurance". Since the need for care is a social risk, it is necessary to provide social security against this risk; also, it can reduce the burden of social assistance because, in the absence of care insurance, only social assistance systems are responsible for people in need of care (Ağören, 2017). Care insurance is an essential social policy tool based on the understanding of providing financial and social support to the state and society, in addition to the individual and their family, of the burden and responsibility of care in case of a need for care (Ağören, 2017; Kocabaş & Kol, 2020). One of the objectives of the 2011-2013 Care Services Strategy and Action Plan of the Prime Ministry Disabled People's Administration [Başbakanlık Özürlüler İdaresi Başkanlığı] (it has now been reorganized under the umbrella of the General Directorate of Services for Persons with Disabilities and the Elderly) (General Directorate of Services for Persons with Disabilities and the Elderly [Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü], 2023b) was to regulate the care insurance within the social insurance system to cover the entire population. Furthermore, in May 2011, it was promised by the head of the relevant unit, who stated that the care insurance would be implemented within three years (Caniklioğlu & Ünal, 2011). However, today, as of last quarter of 2023, the discussions about care insurance in Turkey have not yet been concluded. The Ministry, which plans to implement the Long-Term Care Insurance model in the New Economy Program for the 2021-2023 period, states that it is examining international examples related to the system (ASHB, 2021c; Çalık-Göçümlü, 2021; Ministry of Treasury and Finance & Strategy and Budget Directorate [Hazine ve Maliye Bakanlığı & Strateji ve Bütçe Başkanlığı], 2020).

However, in accordance with the political discourse that tends to position care

within the family, the insurance is titled as "home-care insurance".

Each scheme mentioned above that may relate to disability care is tied to various conditions; among these, citizenship-based, means-tested, and medical disability reports/Special Needs Evaluation Reports for Children come to the fore. Also, although there are various cash transfers and services related to the PwD in Turkey, only cash-for-care among these schemes can be directly associated with disability care.

There is no social assistance program specifically applied to individuals with Down syndrome in Turkey (Grand National Assembly of Turkey [Türkiye Büyük Millet Meclisi], 2020). However, people with DS and their families can benefit from this social assistance and services if they meet the necessary conditions.

Although insurance covers comprehensive medical expenses of children with DS up to age 18 in Turkey, there is a big problem in integrating them into daily life and providing aged care (Tomris et al., 2022). Moreover, it is specified that children with DS are suitable and eligible to receive early intervention services (Majnemer, 1998; Nawi et al., 2013). Early intervention is defined in different ways. According to Bowe (2007), it involves providing services or special programs for children aged 0-3 years old who have developmental issues or are at risk (Bowe, 2007). On the other hand, Watts (1980) describes early intervention as the delivery of therapy or treatment before age four, typically commencing within the first 36 months of a child's life (Watts, 1980). Nawi et al. (2013) have found that both the children's and their families' outcomes improved with the acceptance of early intervention for DS children. Previous research indicates that early intervention yields greater benefits for families, such as having a support system and community involvement. Families of children with DS who receive early intervention experience more favorable outcomes

compared to those receiving less intervention. (Nawi et al., 2013). Thus, to guarantee adequate care for PwD, it is crucial to create assistance that addresses the requirements of family members and find ways to enhance the inherent support systems (Sanderson & Aquino, 2023).

Also, families with children who undergo early intervention often experience a range of outcomes. Tekinarslan (2013) intended to assess the quality of life and levels of depression among Turkish mothers of children with DS, cerebral palsy, and autism spectrum disorder. Accordingly, mothers of children with DS declared notably higher quality of life than other previously mentioned disability conditions (Tekinarslan, 2013).

On the other hand, challenges persist despite Turkey's legal regulations aligning with those of developed nations and a growing focus on studies in the field. These include the lack of a model for an early intervention system, inadequate collaboration among experts and institutions, and a shortage of skilled personnel in the field, all of which are yet to be addressed (Tomris et al., 2022).

CHAPTER 4

METHODOLOGY

In this chapter, the methodology of the study is presented. This chapter includes the research design, the pilot study, the characteristics of participants, and the identity of the researcher.

4.1 Research design

This research study aims to understand the future care planning and social policy expectations of mothers who have children with intellectual disabilities, mainly children with DS, for the times when the mothers cannot continue to care for their children in case of the mother's death or deteriorating health condition. In general, in families with children with disabilities, the current responsibility of care and future care is concentrated mainly on the mother. In Turkey, 91% of those caring for PwD and/or the elderly are women (Turkish Grand National Assembly Equal Opportunities Commission for Women and Men [Türkiye Büyük Millet Meclisi Kadın Erkek Fırsat Eşitliği Komisyonu], 2020). Compared to other family members, the daily life practices, working environments, social lives, and physical and psychological health status of mothers who have children with disabilities are more affected, and mothers stand out as caregivers who play an active role in the care-related processes of their children (Turkish Grand National Assembly Equal Opportunities Commission for Women and Men [Türkiye Büyük Millet Meclisi Kadın Erkek Fırsat Eşitliği Komisyonu], 2020). For this reason, in the current study, interviews were conducted with mothers who have been responsible for the care of their children with disabilities since the day they were born. Also, mothers were

often the primary decision-makers for their children with disabilities in the process of future planning (Arnold et al., 2012; Chambers et al., 2004; Heller & Kramer, 2009; Rawson, 2010; Tozer & Atkin, 2015).

The current study started with a literature search investigating examples of the relevant topic with similar content. The study included recurring and diverging issues related to future care planning and social policy expectations as separate subheadings during the literature review. Afterwards, social assistance and services that PwD can benefit from in Turkey were examined. Thus, social policy approaches that may be relevant to PwD were emphasized, and current practices were listed before exploring related social policy expectations related to these approaches and practices and beyond them. Afterwards, according to the purpose of the current research, data was collected using the qualitative method with a semi-structured in-depth interview method with mothers who cared for their children with DS. Finally, the interviews were analyzed using thematic analysis based on the principles of the qualitative research method, considering the background of the literature review.

As stated, the current research was developed with a qualitative study design that aimed to understand the deeper meanings of human experience than it seems (Krysik & Finn, 2015). The qualitative method emphasizes the participants' subjective explanations and experiences in a particular social context (Denscombe, 2007). Due to its focus on engagement with research participants and emphasis on understanding the participants' real-life experiences, qualitative research has the potential to provide empowerment properties that bring multiple benefits to the participants, service providers, and society at large (Niesz et al., 2008). Thus, qualitative research has the potential to uncover the individuals' perceptions and thoughts about events and social interactions (Agee, 2009; Flick, 2022).

Qualitative research is defined by interviews, which involves answering open-ended research questions by reasoning from parts to a whole, from particulars to generals, or from the individual to the universal (Koch et al., 2014). Formulating a qualitative research question is essential to harness the distinctive strengths of qualitative research (Agee, 2009; Flick, 2022). Effective qualitative questions should stimulate an exploration and discovery process. These questions typically aim to reveal the viewpoints of individuals, groups, or various age demographics (Creswell, 2007).In this research, semi-structured questions guided the interviews. The questions asked in the in-depth interviews have been designed in accordance with the purpose of the research and after the literature review was concluded. The literature review sets the stage for establishing how qualitative research closes those gaps (Kline, 2008). The questions are structured to examine the participants' demographic information, general caregiving experiences, future care plans and social policy expectations.

The interview questions are shared in Appendix A (for the English version) and Appendix B (for the Turkish version). The language of the thesis is English, so the appendices must also be available in English (with the exception of administrative documents such as Ethics Committee Approval). However, the interviews were conducted in Turkish and then translated into English; thus, the researcher created separate appendices for each language version of the semi-structured interview questions.

Moreover, ethical permission was obtained from the Boğaziçi University Social Sciences Ethical Commission to conduct the current research (See Appendix C). Regarding this research study, the application numbered SBB-EAK 2022/90 was examined and found appropriate by the Commission at the meeting dated 21st

December 2022. After obtaining permission from the ethical commission, interviews were conducted.

An informed consent form was used as the instrument in the current study, which the researcher developed according to the aim of the current study. Before the interviews, participants were informed about the interview process, their rights and assured of their confidentiality. Participants were asked to permit audio recording by the researcher at the beginning of the interview and to sign the consent form. It was explained to the participants that the audio recordings would be used to transcribe all the interviews to be able to analyze the data. Also, information was given to the mothers about the confidentiality and storage procedure of the audio recordings. All the participants volunteered to participate in the current research, and they gave permission for the audio recording. When the mothers indicated that they were volunteers, a written consent form (See also Appendix D for the consent form in English and Appendix E for the consent form in Turkish), which included the process of the interview, its purpose and the confidentiality of the research and identity of the researcher, were asked to sign for permitting to attend the research, and also for the audio recording.

The data was protected in a file with a password. The data did not include any information that revealed identity to ensure that the participants' identities were kept anonymous and confidential. After the data collection process was completed, all data were transcribed into a document, and audio records were permanently deleted permanently from the computer. Consent forms and transcript document files were kept in a locker after data analysis was completed.

In this research, designed with a qualitative pattern, the data collected through semi-structured in-depth interviews were analyzed through thematic analysis.

Thematic analysis allows the organization of data at the smallest size and describes it in depth and richly. Compared to other qualitative methodologies, thematic analysis allows the researcher to better understand the subject matter by identifying common themes congruent with the theoretical framework upon which the study is based (Braun & Clarke, 2006). In the thematic analysis method, the most frequently mentioned items across the data set are identified and organized, and these items are turned into themes. The researcher reviews the themes and sub-themes and finalizes the thematization process in a meaningful and concise set of information (Braun & Clarke, 2022).

To reach participants for the study, two kinds of institutions were selected in İstanbul: a non-governmental organization in the field of disability and a special education and rehabilitation center with branches in multiple districts to ensure sample diversity. The reason for preferring these two institutions was that the non-governmental organization has been carrying out studies specifically on DS, and the special education and rehabilitation center has more children with DS than other types of disabilities. The data was collected in February 2023, and then some participants were added in September 2023 to ensure the age diversity of children.

Within the scope of this research, 16 interviews were held, paying attention to ensuring the age diversity of the children. Still, the repetitions of the themes mentioned in the interview attracted attention, and the interviewer felt that data saturation had been reached. Nevertheless, Braun and Clarke (2019) contend that the essence of thematic analysis lies in a subjective process of creating meaning rather than simply extracting data. Therefore, inquiries about sample size and the quantity of datasets lose significance. (Braun & Clarke, 2019).

The researcher needs to become familiar with the data in the initial stage. To achieve this, the data must be transcribed and read repeatedly. During this process, the researcher should engage actively in reading and make notes for use in the next step (Braun & Clarke, 2006). In this research, the researcher conducted and transcribed the interviews herself. Afterwards, the audio recordings of the interviews and the transcripts were checked to see that they were identical, thus increasing the researcher's familiarity with the data. Some notes were taken as suggested during the active reading, and then codes were identified and matched with the related data extracts. The researcher reports the analysis using a concise and logical framework (Braun & Clarke, 2006). Chapter 5 of this study consists of a detailed analysis of the interviews in the context of themes.

The interviews were conducted with the semi-structured in-depth interview technique to understand the future care plans and social policy expectations of mothers who have children with Down syndrome, and as a result of the transcription of the audio recordings of the interviews, a transcript of 167 pages with a total of 72.779 words was obtained. Considering that 16 interviews were conducted to give an idea to those who will conduct similar research in the future, it can be said that the transcript of an interview is 10.5 pages on average and 4548 words on average. The longest of the interviews was 1 hour and 35 minutes; the shortest lasted approximately 40 minutes. Each interview lasted approximately one hour and twenty minutes (including face-to-face information about the research).

Quotations are highlighted as the primary evidence in the qualitative study to elaborate themes and distinguish the voices of the research participants from those of the researcher. Quotations give the heart of the themes or provide striking examples that were sought, identified, and used (Elliot et al., 1999). Since the interviews were

in Turkish, the quotations preferred during the thesis writing phase were translated into English. The researcher did translations, and these translations were approved by the thesis advisor. The participants' quotes used in the current study are also presented in Turkish, the original language of the interviews, in Appendix F. While quotations were used in the current study, the mother's pseudonym and the Turkish version of the quotation were shared in Appendix F, along with the citation number. Additionally, detailed information about the mothers who participated in the interviews was detailed under the next subheading.

Also, member check, also known as participant or respondent validation, is a technique used in qualitative research to ensure the accuracy and trustworthiness of the findings. It involves the researcher sharing the collected data or preliminary analysis with the participants and seeking their feedback and input on the interpretation and findings. By involving participants in the research process, member checking aims to enhance the credibility and validity of the study. During member checking, participants are given the opportunity to review the data or analysis and provide their perspectives, corrections, or additional insights. This process allows researchers to validate their interpretations, verify the accuracy of the data, and ensure that the findings align with participants' experiences and perspectives (Candela, 2019). For these purposes, a member check was made when the current study reached the completion stage and the interviewees were reached again.

4.2 Pilot study

The interview questions of this research, which were carried out with the semi-structured in-depth interview method, were tested in a pilot interview before the

regular interviews started. The purpose here is to test the functionality of the questions and their suitability for the purpose of the research. For this purpose, the pilot study participant is a mother with a child with DS who adopts a rights-based approach in the field of disability and care policy and engages in activism. It was essential to conduct a pilot interview with someone knowledgeable in many aspects of the field of disability and care in general to test the suitability of the questions for the purpose and check whether the tone of the questions was correct.

The pilot study participant stated that all interview questions were clear and appropriate. After the pilot study, interviews were arranged with other participants with the thesis advisor's approval. The pilot study interview took 1 hour and 35 minutes, but other interviews were completed in about an hour.

4.3 Participants

The primary data source for the research was mothers who were the primary caregivers of their children with disabilities to explore future care planning and social policy expectations for children with disabilities as the subject of the research. As previously highlighted, two kinds of institutions were chosen in İstanbul to reach the participants to ensure sample diversity: a non-governmental organization in the disability field and a special education and rehabilitation center with branches in multiple districts. The first communication with the potential participants was established through these mentioned institutions. The researcher contacted the institutions through e-mail and telephone, and then a face-to-face meeting was held in which the research details were explained. After meetings with institutions where mothers with DS exist, they told the mothers about the subject of the thesis research and, with the approval of the mothers who wanted to participate in the research, their

contact information was shared with the researcher. Accordingly, the researcher called the participant mothers, briefly explained the research again and confirmed their willingness to participate. Afterwards, an interview was planned at the most suitable place and time for the participant.

A total of 30 potential participants were contacted, but 14 of them did not participate for various reasons. The main reasons for those who did not participate were that either their children or they were sick, or their relatives had surgery, they had to change cities or move, or they had other work to do at the time of the appointment. As a result, interviews were held with 16 mothers who volunteered to participate in the study.

Oral and written information about the study was given during the interviews. The interviewees were also informed that participation in the research was voluntary, and also informed about its subject and purpose, and that the information obtained during the interviews would not be used for purposes other than the purposes of the research. In addition, information about institutions where they could get free psychological support in case when the research content triggers negative feelings of the mothers was given in the informed consent form, as can be seen Appendix D (for English), and Appendix E (for Turkish). It is stated that the participants can have the right not to answer any question and withdraw from the interview at any stage if they like.

The researcher wants to reveal the desiring care of mothers for their children by focusing on the future care plans and social policy expectations of mothers with a child with DS. At this point, it was important for research that mothers to have different backgrounds to reach different future plans and social policy expectations. For this reason, the mother's marital status and the father's and siblings' contribution

to the caregiving processes were explicitly examined. In addition, in this research, which aimed to explore future planning and social policy expectations, it was essential to have general information about the socio-economic situation of families since it directly affects future planning and social policy expectations. It was imperative to know the current social assistance and services they benefit from and to discover the opportunities they can offer their children in the future. Another variable related to care planning and social policy expectations was the age of the children. The child's age variable varied greatly concerning performing self-care skills.

Since the most diverse variable is the children's age, the participating mothers' information was listed, taking into account the ages of their children. Accordingly, mothers were given pseudonyms based on the age of their children, from youngest to oldest, for example, starting from Mother 1 and continuing to Mother 16. Likewise, children are referred to in the same numerical order as their mothers, starting from Child 1.

General information about the mothers and their families is presented below. Besides their first feelings, the reactions and thoughts about when they first learned that their child was a baby with DS are also included, along with their own expressions. In addition, the quotes used by the participants are presented in Turkish, the original language of the interviews, in Appendix F, and the quotes are numbered sequentially, starting from one.

Mother 1 is 38 years old, and her son with DS is 2.5 years old. Mother 1, a high school graduate, does part-time bookkeeping for her own business. In her own assessment, she defined her socio-economic status as upper-middle. She does not have any known chronic illness.

She is married to the father of her child, and the father is 45 years old. She was 35 years old when her son with DS was born. Also, Mother 1 has two other sons, 13 and 17 years old. They learned that their child had DS in the 7th month of her pregnancy. She expresses her feelings and thoughts about the first time she learned it as follows:

> We were shocked that day. My husband was even more shocked. He couldn't even talk at all. So that day, he couldn't even say a word. After that, we said that this child is ours no matter what, but we were still very hesitant until it was born. My own gynecologist is my close friend; she said that you know, some doctors say it's 100%, but the child could also be normal. We hoped he might be normal, but to be honest, I always thought he had Down syndrome until the last moment (Mother 1) (Appendix F, 1).

Mother 2 is 35 years old, and her son with DS is 3 years old. Mother 2, a high school graduate, attended courses on child development given by the municipality. She has never worked before. In her own assessment, she described their socio-economic situation as middle-class. She gets cash-for-care. She has no known chronic illness.

She is married to the father of her child, and the father is 39 years old. She was 32 years old when her son with DS was born. Also, Mother 2 has two other sons, who are 6 and 9 years old. It was discovered that Child 2 was a baby with DS at the day he was born, but they did not tell Mother 2 immediately. She expresses her feelings and thoughts when she first noticed it as follows:

> I was more familiar with the name (Down syndrome) because I had received child development training. In fact, I had such a special interest in those children that I both loved and felt sorry for them. They did not tell me at first that he had Down syndrome because he was in intensive care. However, I understood when I first saw him. When I went and saw him in intensive care, I asked the nurse if my baby had Down syndrome because of his skin color and shape of his eyes... I realized it myself, and it was never told to me. … Afterwards, we already started our journey. But it was difficult. Of course, there are still difficulties. But of course, it was difficult when I first heard it. I do not know which was more challenging: to accept it or the mother's sadness. My feelings were very mixed. Frankly, it still is (Mother 2) (Appendix F, 2).

Mother 3 is now 40 years old. Her son, Child 3, who has DS, is now 6 years old. Mother 3 was illiterate, but she learned it herself later. She's never worked before. In her own assessment, she defined their socio-economic status as low. She gets cash-for-care. Her husband did not have insurance until four years ago, and they live in a rented house. She has no known chronic illness.

She is married to the father of her child; the father is 38 years old. She was 34 years old when her son, who had DS, was born. Also, Mother 3 has two daughters, ages 9 and 11. It was discovered that Child 3 was a baby with DS the day he was born. She expresses her early feelings and thoughts as follows:

> I fell apart. I could not eat or drink water. I was shocked. My tears did not stop for 4 months. And then, a nurse came and showed me another child with Down syndrome, and she said, "Look, your child will be like this too." Then my tears stopped. If this is the case, why am I crying? … Of course, my husband also panicked. He said " I do not have a son to care for him; after all, who will take care of my child if I die?'' I say we are young at the moment. If you die, I will be here. If I die, you will be here (Mother 3) (Appendix F, 3).

Mother 4 and her husband are 35 years old, and their daughter with DS is 7 years old. Mother 4 has a master's degree and works as a teacher in the public sector, in the Science and Art Center, the public institution for gifted education. After giving birth, she extended her maternal leave for 45 days with the medical committee's report and then continued her routine work. She can consider herself socio-economically upper- middle. However, she added:

> Because my husband works in the private sector, he earns better than me, who is a civil servant. Of course, we see the advantages of this for Child 4's education (Mother 4) (Appendix F, 4).

After Mother 4 gave birth to her daughter, at the age of 28, she carried out significant activities to raise awareness in the field of disability. They do not want another child. She has no known chronic illness. Although there was concern during the pregnancy that their daughter was a baby with DS, they were sure after birth.

> We have a story of two different doctors: one who measured my daughter's nuchal translucency and one who did not. Although the doctor who measured it correctly reported this to my own doctor, the doctor who could not measure it, we were not given any additional tests despite our request. … So, there was a doubt beforehand. Down syndrome was in the back of our minds, but we learned it after birth (Mother 4) (Appendix F, 5).

Mother 5 is now 41 years old, and her son with DS is 8 years old. She is a primary school graduate and a housewife. In her own assessment, she described their socio- economic situation as middle-class. She gets cash-for-care. They live in the house they inherited from her father. She has no known chronic illness.

She is married to the father of her child, and the father is 43 years old. Mother 5 was 33 years old when Child 5 was born. Mother 5 has another daughter who is 19 years old and she is currently a university student. She learned that Child 5 was a baby with DS when the midwives held the baby after giving birth. She expresses her early feelings and thoughts as follows:

> I never knew before. You know, I was seeing those children from afar. When it does not happen to you, you do not know exactly what it is and what it is not. They did not tell me directly, but they told my husband. My husband came directly to me before the child came to me. I looked at my husband, and he was pale. I asked, "What happened, there is something wrong. The other kids came, and mine did not." My husband said, "They say our child maybe eighty per cent having Down syndrome; when he has Down syndrome, he would be disabled." I mean, at that time, I was so devastated. I cried and felt sad, so I can say that it lasted 6 months. … When a woman in our neighborhood learned that I had given birth like this, she came immediately and told me that he would not be able to walk or talk. She told me so many bad things that I was extra devastated and ruined. … Of course, I was upset because I did not know what it was (Mother 5) (Appendix F, 6).

Mother 6 is 37 years old; her son with DS is now 9 years old. Mother 6, a high school dropout, worked for seven years while she was single. Later, there was a period when she worked in a kindergarten to be with her son, who had DS. In her own assessment, she described their socio-economic situation as middle-class. She gets cash-for-care. She has no known chronic illness.

She is married to the father of her child; the father is 42 years old. She was 28 years old when her first child, who had DS, was born. Mother 6 has another 6-year-old daughter. She described the time when she learned that her first child was a baby with DS as follows:

> It turned out to be risky in the quadruple screening test in the womb, but we said we would accept it no matter what. So, we didn't do anything after the quadruple scan. We waited for him to be born. He was born at 36 weeks. … Of course, we were upset when he was born with Down syndrome… But we were not shocked; we were expecting it. Thank goodness, I have never experienced such devastation, but of course, you are affected psychologically (Mother 6) (Appendix F, 7).

The difference between Child 6 and the children of other participating mothers was that he had Translocation DS, which means that the recurrence of DS at the second birth is high (Flores-Ramírez et al., 2015; Turkish Fetal Medicine and Perinatology Association, 2020). However, medical geneticists can help parents assess the risk of having a second child with DS (Turkish Fetal Medicine and Perinatology Association, 2020).

Before giving birth to their second child, Mother 6 and her husband had tests to determine their carrier status both checked in Turkey and abroad, and then gave birth to a second child when they learned that they were not carriers. Mother 6's statements regarding this issue are as follows:

> We wanted the second child to support Child 6 and to support his development, and we consciously decided to give birth to her. It was very good, thanks God she also brought life to her big brother, Child 6. Child 6 was diagnosed with leukemia during the pandemic. It's been 4 years since he received a bone marrow transplant from his sister. So, his sister gave him a chance to live (Mother 6) (Appendix F, 8).

Mother 7 is 43 years old, and her son with DS is 10 years old. Mother 7, a primary school graduate, previously worked as a cleaner in a kindergarten. In her own assessment, she described their socio-economic situation as middle-class. She

gets cash-for-care. She had problems with blood pressure and diabetic symptoms after giving birth to her child with DS.

She is married to the father of her child; the father is 42 years old. She was 33 years old when her son and last child, who had DS, was born. Mother 7 has a 13-year-old daughter and a 16-year-old son. She learned that her child had DS after birth. She expressed her feelings and thoughts about the first time she learned it.

> The moment he was born, the doctor's face was astonished. He said, "This child has Down syndrome" and that's how we met Down syndrome. When my child was born, I did not know what Down syndrome was. Yes, I was seeing them but I did not have direct contact and I did not know what they were like. My brother-in-law said that if we had known it was like this, we would have had an abortion. From there, I realized that the situation was very serious. There I realized that I really had a difficult process ahead of me (Mother 7) (Appendix F, 9).

Mother 8 is 49 years old, and her daughter with DS is 15 years old. Mother 8 is a university graduate. She was working before her first daughter with DS was born, and after she was born, she became interested in rights advocacy in the field of disability. She does not have any known chronic illness. In his own assessment, she described their socio-economic status as upper-middle but also added:

> The total income of our family is high. But this is sustainable only as long as both I and my husband work. In other words, we do not have the opportunity to maintain this situation when one of us is not working (Mother 8) (Appendix F, 10).

Mother 8 is married to the children's father; the father is 51 years old. She was 34 years old when her first child, who had DS, was born. Mother 8 has another 11-year- old daughter. She described the time when she learned that her first daughter was a baby with DS and the aftermath as follows:

> When I first heard about it, I was very sad. We were also worried and afraid at the same time. First of all, we did not know what Down syndrome was, so we had a fear. We didn't know what we were facing. The second was the fear of being excluded from our environment. Thirdly, I always thought of the figure of the village madman in the Yeşilçam movies (a kind of cinema culture) and his/her family and so on... Such a state of anxiety, a sense of

> failure, etc., all together. It was more like this was a nightmare that would pass when you woke up.
> … But of course, in those first feelings and thoughts, what will happen in the future, the anxiety was overwhelming… You know, the fear of "what will happen if we die for a very newborn baby?" I mean, then the decision that we will always be with her and support her comes quickly, but then emotional ups and downs continue for a certain period of time I mean, I can say that the initial feelings do not always last, they sometimes flare up again (Mother 8) (Appendix F, 11).

After Mother 8, children of mothers were over age 18. Therefore, disability percentages would be assigned. The disability percentage for individuals under 18 has not been specified in their medical report. Thus, before Child 9, the disability percentage of children was not specified. As mentioned in Chapter 3, the disability status of children is evaluated with ÇÖZGER; the special needs levels of children are determined without specifying the concept or percentage of disability. Special needs levels have been identified with the statement that all children from Child 1 to Child 9 require special needs conditions.

Mother 9 is 58 years old, and her daughter with DS is 22 years old. Mother 9 is a primary school graduate and a housewife. In her own assessment, she described their socio-economic situation as middle-class. She gets cash-for-care. She has no known chronic illness.

She is married to her child's father, who is 65 years old. She was 36 years old when her daughter, who had DS, was born. Child 9's disability report states as 80% for disability percentage. Mother 9's husband had a second marriage and has two sons from his former wife. He also has a son and a daughter with DS from his current marriage to Mother 9. So, Child 9 is the youngest and only girl; she has three older brothers. Mother 9 expresses her first feelings and thoughts about the first time she learned that her daughter had DS and then how her life changed and experiences afterwards.

> It was very painful for me. Two doctors stood over me. They asked questions: is there a consanguineous marriage, how old are you, are there any people with disability in the family? I said, "Where is my daughter? I want to see my daughter." The doctor said my daughter was born with Down syndrome. I have never heard of it before. I said what is that? She literally said to my face, "Your daughter is mentally retarded." That's what she said. My psychology was ruined, I was destroyed... My mouth shut, and tears started to flow from my eyes. I could not hold back my tears. Yes, I know there are children with disabilities, but I had never heard of Down syndrome. I did not know what it was. It has a different name too, I said; what is it? After that statement, everything she said felt like a slap in the face. I felt like that. My neighbor had two daughters, both of whom were bedridden. Those children came to my eyes.
> Then, we went to the genetics department at a university hospital. There was a psychiatrist there. She told us, "The fault was neither in the mother nor in the father; there is not your fault. This is a gift that God gave you," she said. When she said that, my sun suddenly rose again. I swear I was living in darkness. One doctor set my sun down; another doctor took my sun out (Mother 9) (Appendix F, 12).

Mother 10 is 52 years old, and her son with DS is 23 years old. Mother 10, a high school dropout and housewife, described their socio-economic status as middle-class in her own assessment. She has no known chronic illness.

She is married to the father of her children, and the father is 56 years old. Mother 10 was 29 years old when her son, Child 10, who had DS, was born. Child 10's disability report states as 55% for disability percentage. Additionally, Mother 10 has a 28-year-old daughter. She described the time when she learned that her son was a baby with DS and the stated as follows:

> I did not get tested or anything. So, my doctor did not say I needed to get tested, so I did not. If I had known, I probably would have had testing done. When I first heard about it, there was no one around us with Down syndrome. Of course, we were shocked. My husband was even more shocked, but I was calmer, more stoic. I accepted quicker because I realized that he came as a gift from God, and I am glad I have my son (Mother 10) (Appendix F, 13).

Mother 11 is 50 years old, and her daughter Child 11, who has DS, is 24 years old. Mother 11, a secondary school graduate, worked for a while before marriage. In her own assessment, she described their socio-economic situation as

middle-class. She has a high blood pressure. Her daughter, Child 11, has a history of leukemia. Child 11's disability report states as 51% for disability percentage.

She is divorced from the father of her children. Mother 11 was 26 years old when Child 11 was born. Mother 11 also has a 23-year-old son. She learned that her daughter was a baby with DS during the triple-screening test. She describes those times as follows:

> I gave blood for the triple-screening test. On the way back, I bought a "My Baby" magazine and as I was turning the pages, I suddenly saw an article about people with Down syndrome. I started reading it, and there I read about people with Down syndrome for the first time. I was wondering why these children look alike...
> Then, two weeks later, it came out that she might have Down syndrome. Along with that serious shock, I also experienced something different. They said, she might have Down syndrome, but we cannot be sure, amniocentesis is required. Then they explained the abortion process. This scared me a lot. When the doctor explained this to me clearly, I had already made my decision. Then Child 11 was born at seven months old, so there is a story like this (Mother 11) (Appendix F, 14).

Mother 12 is 55 years old, and her daughter with DS is 25 years old. Mother 12, a primary school graduate and housewife, assessed her socio-economic status as lower- middle. She gets cash-for-care. Mother 12 underwent cancer treatment. Her daughter, Child 12, has diabetes, and the disability report states as 70% for disability percentage.

She is divorced from the father of her child. She was 30 years old when she gave birth to her last child, Child 12. Mother 12 has two daughters and three sons, a total of 5 children. Mother 12 learned that Child 12 had DS after birth, when she went to get a regular health check of Child 12.

> We were just getting my daughter's injections. Then the doctor said your child is " Mongol[3]". I said, "What does Mongol mean, doctor?" We did not

[3] Down syndrome was also known as “Mongolism”, and people with Down syndrome were referred to as “Mongoloids/Mongol’’. However, the use of the word was stopped after criticisms about referring to a discriminating title. The use of the term “Mongolism” diminished progressively and disappeared

> know what it was before. "She has Down syndrome," he said. Then his father asked questions, we were together with the father at that time. The doctor said that more than half of such children have a hole in their heart, thanks God yours does not have such a thing. But God knows if there will be a problem in the future, he said. He said you will be thankful every day. Do not worry, she will learn a word every day... The doctor really knew it, she really learned a word every day (Mother 12) (Appendix F, 15).

Mother 13 is now 58 years old, and her daughter with DS is 25 years old. She is married to the father of her child; the father is 61 years old. Mother 13, who was 33 years old when Child 13 was born, she has two more daughters. The youngest daughter, Child 13, is 25, and Child 13's older sisters are 29 and 30, respectively.

Mother 13 received cash-for-care before the older sisters started working. In her own assessment, she described their socio-economic situation as lower-middle socio-economically. Mother 13 learned that her daughter was a baby with DS during a doctor's examination on the day she was born.

> When the doctor quickly brushed it off, I asked the nurse what the doctor meant, and she said it could be mental retardation. Then, of course we got upset, and I immediately started thinking about what I could do. Until then, I did not know what Down syndrome was. In the past, they used to put them all in the same category; it was not known whether the child was autistic or had Down syndrome. Now, of course, people are more conscious (Mother 13) (Appendix F, 16).

Mother 14 is 61 years old, and her daughter, with DS, is 26 years old. She is married to the father of her child, and her husband is 58 years old. They have their own business, are both architects, and deal with restoration work. She considers herself upper class. She has two daughters. Child 14 has an older sister. Child 14's disability report states as 40% for disability percentage. She learned that her daughter was a baby with DS after birth.

> We found out after she was born that she had Down syndrome; we had done all the tests before she was born, but nothing was found. Then they noticed it as soon as she was born, and as I was waking up, I heard voices saying "take

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in the early 1980s; since then only been used in articles concerning the history of the syndrome (Allen et al.,1961; Ataman et al., 2012; Rodríguez-Hernández & Montoya, 2011).

> blood and take it away" etc. Then my husband told me. Of course, I experienced the biggest shock of my life, at that moment. I do not know; it was a moment I had never experienced before in my life. … We thought that the age gap between my eldest daughter and my second child would be small, so they would be friends. So that was our main goal. But will she be a burden on her sister? That was my first thought. Because until then, I honestly had no knowledge about Down syndrome... I saw it one by one around me, but after Child 14 was born, I started seeing it much more. To be honest, I didn't have much awareness until then.
> Ten or fifteen days after she was born, we took her to a doctor at a university hospital. He asked me if I had any other children, and I said yes. He said, "Okay, forget about the child with Down syndrome, give birth to another one because nothing will come of it." He told me, "Do not labor in vain." And after that, I became so ambitious... I mean, I really hated it... And even though there were many doctors in my family, including my father, I developed such a negativity towards doctors (Mother 14) (Appendix F, 17).

Mother 15 is 53 years old, and her son with DS is 27 years old. She is a primary school graduate and housewife. She is married to the father of her children, and her husband is 63 years old. She considered herself to be in a middle-class socio-economic situation. They were receiving cash-for-care before Child 15 started working. Mother 15 has another son who is 32 years old. Child 15's disability report states as 70% for disability percentage. She learned after birth that her child had DS.

> When I went for the first vaccination after birth, the pediatrician looked into the palm of his hand and said, "Take this child to a university hospital." When I asked, "What's wrong with him?" he said he might be disabled. Of course, I started crying at that moment. Tests were conducted at the university hospital, then the doctor told me that these are children to be trained, just like cats and dogs are trained... If you also provide training, you can integrate them into society (Mother 15) (Appendix F, 18).

Mother 16 is 60 years old, and her son with DS, is 35 years old. Mother 16 is married to the father of her children, who are at the same age. She has two children. Her son with DS is 35 years old, and her daughter is 30 years old. Mother 16 was 25 years old when Child 16 was born. She considered herself to be in a middle-class socio- economic situation. Child 16 is working; she received cash-for-care before her son started working. She learned that her child had DS the moment she gave birth,

and his disability report states as 70% for disability percentage. She expressed the initial processes as follows:

> I gave birth in a public hospital. The moment my child was born, the assistants immediately told me that my child was disabled and would never be a normal child. That's what the doctors told me. I immediately passed out right there. Then we go from doctor to doctor and everywhere. … Then we finally went to a doctor. He said, "Do not take your child from place to place, from doctor to doctor." He said the only thing that will be good for this child is education. Education. … Afterwards, I started attending pieces of training and took him wherever there was training (Mother 16) (Appendix F, 19).

General information about mothers and their first evaluations of their babies with DS are mainly highlighted. In summary, Table 2 briefly lists the mother's age, marital status, cash-for-care beneficiaries, children's ages, children's gender, and information about the mother's other children.

Table 2. General Information of the Participants

Participants	Mother's age	Child's age	Child's gender	Marital status	Cash-for-care beneficiaries	Other children
Mother 1	38	2,5	Male	Married		2 boys
Mother 2	35	3	Male	Married	√	2 boys
Mother 3	40	6	Male	Married	√	2 daughters
Mother 4	35	7	Female	Married		
Mother 5	41	8	Male	Married	√	1 daughter
Mother 6	37	9	Male	Married	√	1 daughter
Mother 7	43	10	Male	Married	√	1 daughter
Mother 8	49	15	Female	Married		1 daughter
Mother 9	58	22	Female	Married	√	3 boys
Mother 10	52	23	Male	Married		1 daughter
Mother 11	50	24	Female	Divorced		1 daughter
Mother 12	55	25	Female	Divorced	√	1 daughter and 3 boys
Mother 13	58	25	Female	Married		2 daughters
Mother 14	61	26	Female	Married		1 daughter
Mother 15	53	27	Male	Married		1 boy
Mother 16	60	35	Male	Married		1 daughter

As stated before, 16 mothers living in İstanbul and having children with DS voluntarily participated in the current study. The age range of DS children of mothers participating in the current study was between 2.5 and 35, and the ages of the mothers ranged between 35 and 61. Also, seven children were girls, nine were boys, and eight were under 18; the remaining 8 were adults.

Moreover, two mothers were divorced, while the rest were married to their children's fathers. However, all participating mothers were living with their children with DS. Among the participating mothers, only Mother 4 had an only child, while

all the remaining mothers had other children with typical development in addition to their children with DS.

Furthermore, seven mothers were still receiving cash-for-care when the interviews were conducted. It was stated that the mothers were predominantly middle class according to their socio-economic status assessments. One mother evaluated her socio-economic status as low, two as lower-middle, eight as middle, three as upper-middle, and one as upper. Additionally, the children of Mother 13, Mother 15 and Mother 16 were working at the time of the interview.

Mother 1, Mother 6 and Mother 11 learned that their child would be a baby with DS during prenatal screening tests. Although Mother 4 had a suspicion of DS before birth, she was certain after birth that her child had DS. In summary, the remaining 12 mothers learned that their child had DS after birth, usually by medical authorities.

It is worth noting that the participating mothers generally made arrangements for the interview place and time, considering their children's care responsibilities.

This also enabled the researcher to observe the bond of mothers' care responsibilities. For example, Mother 3, who stated that she could not hold an interview outside because she could not leave her 6-year-old son with DS, were interviewed in their own home setting.

> He is helpless alone, so I cannot leave him. That's why when you said let's interview outside, but I cannot leave. My little girl will be at home, but if I leave Child 3 to her, what will I do if she gets caught up in the game and Child 3 hurts himself? If it were his older sister, I would let him go because she always keeps an eye on him. If he goes somewhere, his older sister follows right behind. However, my little daughter says: "Why do I have to care for him?" (Mother 3) (Appendix F, 20).

Also, Mother 14 came to a cafe in the mall for the interview because she stated that she could not leave her daughter with DS alone at home. During the

interview, the child spent time at another table so that he could not hear the mother and the researcher. Interviews were held with the remaining mothers in available rooms at the special education and rehabilitation center or online.

4.4 Identity of the researcher

As a qualitative researcher, researcher is aware of the probable impact on every aspect of the research, ranging from their interactions with research participants to how the researcher's thoughts and life experiences predispose them to specific perspectives and interpretations of qualitative data. Reflexivity involves thoughtful self-reflecting of one's biases, theoretical predispositions, and both professional and personal orientations concerning the subject under research. This self-reflection considers how these factors can potentially impact the process of collecting and analyzing data (Palaganas et al., 2017). Reflexivity in qualitative research requires openness to critically examining how one's own subjectivity influences the research (Koch et al., 2014). Thus, related to the researcher's identity, the researcher's own thinking and life experiences should be briefly highlighted. Also, as emphasized before, thematic analysis was performed in this research, and subjectivity is essential in thematic analysis because the researcher actively and directly generates the themes (Braun & Clarke, 2022).

The most crucial issue of reflexivity is related to my potential as a researcher to be one of the relevant subjects of this research topic since I have a sister with DS (as a family member an older sister who can be included in future care planning).

Before starting the research, I thought that this situation would cause me to be affected by emotional burden more than expected, especially during the interviews I

would conduct, and that I would feel the need to take a break from time to time. Nevertheless, it did not happen that way.

On the other hand, the sensitivity brought about by my potential to be one of the people who have a sibling with DS and who can be prominent in future care planning manifested itself not during the interviews but during the literature review. All in all, due to my interest, I came across sources related to the increased life expectancy of PwD. However, while it is emphasized that the life expectancy of individuals with DS is extended, the fact that they suffer from dementia very seriously in their advanced ages was a fact that demoralized me and made me question the care needs of these people in their later ages. In other words, while trying to discover the future care planning and social policy expectations of mothers who have been caring for their children with intellectual disabilities in a world where they do not have primary caregivers, there is another care issue that I know requires special care and has various difficulties beyond the disability of the individual in need of care. It made me think about it a lot; therefore, I needed to take a break and get support during and after the literature review. These interim and support processes impacted me not being negatively affected by the interviews in the later stages of the current thesis study.

Similarly, I think that I was able to go through the research processes more efficiently because my thesis advisor has a background in clinical psychology/psychological counseling and guidance and gave me space to express myself in a way that is related to and not limited to the thesis research. Thus, appreciated to the guidance of the thesis advisor, the researcher's processes ensure rigor and quality.

Eventually, interviews with the mothers of children with disabilities were analyzed, and the current study's findings are given in the next section.

CHAPTER 5

FINDINGS

The current study aimed to examine the future care plans and social policy expectations of mothers for their children with DS, in case they die earlier than their children do or their health conditions deteriorate. For this primary aim, sixteen mothers were interviewed through the semi-structured interview forms prepared by the researcher. The interviews were analyzed using thematic analysis based on the principles of the qualitative research method. The interview findings are presented under four main themes in this chapter. These are namely; evaluation of mothers' care needs regarding their children with DS, the mothers' concerns associated with the future of their children with DS, future care planning of mothers and social policy expectations of mothers.

When presenting the findings, quotations were provided from the participating mothers' verbal statements. As mentioned before, each participant was given a code name starting from Mother 1 to Mother 16 to ensure anonymity. A numerical identifier was assigned to the original Turkish quotations, which were included in Appendix F, while the quotations in English were provided in the main text.

5.1 Evaluation of mothers' care needs regarding their children with Down syndrome

This section highlights mothers' evaluations regarding their children's care needs. Learning to assess children's care needs was deemed necessary to understand mothers' future care planning and social policy expectations in the following sections.

American Association on Intellectual and Developmental Disabilities (AAIDD) (previously known as American Association on Mental Retardation) outlines defining intensities based on the amount of support for PwID. Intensities based on the amount of support describe the framework of PwID and provide a universally applicable and effective model for the classification, diagnosis, and planning of support for PwID. Additionally, it offers the opportunity for a deeper comprehension of the dynamic interaction between the individual, their environment, and the specific profile and level of support required (American Association on Intellectual and Developmental Disabilities [AAIDD], 2002).

The support approach involves assessing each person's unique requirements and recommending methods, services, and assistance to enhance their capabilities, acknowledging that these needs and situations may evolve. According to AAIDD, it encompasses the tools and personal approaches essential for fostering the growth, education, interests, and overall welfare of individuals with intellectual disabilities. This support may come from various sources, including family members, friends, educators, psychologists, medical professionals, or suitable organizations (Schalock & Luckasson, 2004). In the current study, it is seen that the mothers supported their children with DS. Table 3 shows the adapted form of AAIDD classification based on levels and areas of support for PwID. Levels of support range from intermittent (just occasional or “as needed” for specific activities) to pervasive (continuous in all realms of living) (AAIDD, 2002).

Table 3. Levels and Areas of Support for Intellectual Disabilities

Level of support	Duration of support	Frequency of support	Setting of support
Intermittent	Only as needed	Occasional or infrequent	Usually only one or two
Limited	As needed, but sometimes continuing	Regular, but frequency varies	Several settings, but not usually all
Extensive	Usually continuing	Regular, but frequency varies	Several settings, but not usually all
Pervasive	May be lifelong	Frequent or continuous	Nearly all settings

(AAIDD, 2002)

As detailed in Chapter 4, since the age range of participating mothers' children is vast (2.5-35), the intensity of their children's care needs also varies. Considering the mothers' evaluations, the intensity of care needs among children varies according to age groups. Although extensive/pervasive care is required during infancy, as detailed below, mothers tend not to evaluate the care needs of their babies with DS differently than their typically developing babies. However, mothers underlined the extensive care needs of their children with DS after the infancy period. Mothers with adult children generally stated that they provided intermittent support when necessary.

However, there are different evaluations between the home and out-of-home environments. Another study conducted with mothers of children with DS also distinguished the infancy and childhood periods. It stated that the group of children with DS aged one to three years old always required intensive care, while children

with DS in the age group of four to six years and seven to twelve years were very active (Sari et al., 2006).

The ages of the children of the mothers participating in the current study vary. In parallel, the fact that the self-care skills of the participants' children (such as the ability to walk on one's own, go to the toilet on one's own, dress on one's own, and eat on one's own) differ is also important in terms of diversifying the future care planning and social policy expectations that mothers consider for their children. Moreover, it also changes the intensity of care the child needs, as participants' mothers were highlighted.

Mother 1 and Mother 2's children are the youngest children and need extensive or pervasive care from their mothers due to their young age. Considering they are still babies; the participating mothers did not evaluate their care responsibilities for their children with DS differently than they did for their other children.

> To be honest I do not see much of a change mentally. Because Child 1 is a very understandable baby, a baby that does not tire us at all... But if you say there should be a difference, I think the only difference between when my other children were two years old and Child 1 when he is two years old is that he cannot walk now. Because, in general, he is a very perceptive child. Of course, we are trying to give him all the education we can so that he can become a better individual in the future, able to stand on his own feet. (When compared to my other children) What was different was that processes such as physical therapy and education started in the third and fourth months (Mother 1, 2-year-old boy[4]) (Appendix F, 21).

> If you ask me what is the difference between Child 2 and my other children... He has facial resemblance to those with Down syndrome and his attendance at special education. Other than these, he is no different from my other children. Whether sleep routine or having other characteristics are the same as my other children. But my other children did not use diapers at his age, and they had received toilet training. Plus, they had richness in vocabulary. Of course, we have that deficiency, but other than that, he is like a normal baby.

[4] In the quotations between Appendix F, 21-Appendix F, 37, information on the age and gender of the children are also included, as these may be important variables in the evaluation of mothers' care needs regarding their children with Down syndrome.

> There is no noticeable difference from other children in terms of serenity, sleep, and getting along with his brothers (Mother 2, 2,5-year-old boy) (Appendix F, 22).

While caring for their babies with DS, Mother 1 and Mother 2 did not experience a very different caregiving process than their other children, other than early education and the delay in the developmental processes generally expected from their same age peers. The reason for this may be related to the fact that every baby needs the mother's care (Sari et al., 2006). However, as mentioned next section, as children with DS get older, the gap between the developmental processes other peers widens, and differences in the mother's caregiving process may become more observable at later ages.

It can be observed that in later childhood, mothers take on more care responsibilities for their children with DS compared to their typically developing children. In this case, mothers have comprehensive responsibilities, from meeting the needs of their children's care in the areas of toileting, feeding and dressing, and ensuring their safety. These findings indicate that mothers' level of support is extensive, and the duration of support is usually continuing (AAIDD, 2002).

> For example, my child cannot express himself and cannot want even water. I am changing his diaper. We feed him, we cook something for him, we give it to him. When he is alone at home, he opens the door of the balcony and throws everything away. I am afraid he will throw himself, too. We cannot open the window. When someone is with him, we look after him and open the door. I do not care about anything; he may harm himself. He is helpless alone, so I cannot leave him (Mother 3, 6-year-old boy) (Appendix F, 23).

> She is currently going to primary school, and I go with her. Because I do not believe that she can stay at school alone even though she is a student in inclusive settings. Therefore, for security reasons and basic care needs, I wait with her at her school. I wait at the school's teahouse during her school days and lesson hours. We are together during breaks. So, I have no one to leave her to; that's why I go to school with her in the morning, and she comes to my school with me in the evening [mother is a teacher in the public sector].
> I am at her school until half past two. My lessons start at half past three. This time she is coming to my school with me. We all attend my classes together. I

> also observe her when I give my own lessons. She is just standing next to me, she's staying next to me for safety reasons. I do not let her wander around the school corridor while I am in lesson (Mother 4, 7-year-old girl) (Appendix F, 24).

> I am responsible for Child 5's eating, I'm responsible for his sleeping. Everything is on me even dressing. My son has a problem with eating, and he has a problem with his intestines, so my son just started eating regular food this year. It has been for 6-7 months, and we stopped feeding him with baby food. He is progressing very slowly, but he is progressing forward (Mother 5, 8-year-old boy) (Appendix F, 25).

> Now, for example, I diaper him at night before bed. Usually, if someone else does the diaper, they do not apply cream or powder. For example, let's say they do not apply it... He is a child with very white skin. His skin is very delicate, and he gets reddening of the skin immediately when he urinates... I do not feel comfortable, so I care for everything about him (Mother 5, 8-year-old boy) (Appendix F, 26).

> You always have to keep an eye on him because he is very hyperactive. … For example, he goes to the toilet; he can use the wipes. But if he could not see wipes, he took clothes from the dirty clothes basket and wiped with it. We must always keep an eye on him (Mother 6, 9-year-old boy) (Appendix F, 27).

> You do not know what he will do and when, you cannot predict what will happen five minutes later. We need to keep an eye on him at all times (Mother 7, 10-year-old boy) (Appendix F, 28).

The intensity of caregiving for mothers with children with DS may differ compared to mothers with typically developing children of the same age. However, mothers with children aged 15 and over, when evaluating how much their children need their care, used general statements that they met their children's care needs not always, but within their demands and when necessary. According to the framework of the AAIDD (2002), this can be considered intermittent.

> This is actually a somewhat controversial question. … She is a child who mostly handles her own self-care. But for example, she asks for help when necessary and says, "Mom, help me" (Mother 8, 15-year-old girl) (Appendix F, 29).

> He does not need my help; not now. Of course, there were times when he was little and needed my help; but now he can do everything himself. Actually, he helps me. He is my biggest helper in everything. Even though he is a boy, he is a very neat, orderly child (Mother 10, 23-year-old boy) (Appendix F, 30).

> Currently, she does everything by herself, on the contrary, she gets angry when we interfere (Mother 14, 26-year-old girl) (Appendix F, 31).

> He generally handles his own care. He shaves and bathes himself; that is, he also does his own self-care. He breaks eggs for himself, dish with egg, and makes lovely salads (Mother 15, 27-year-old boy) (Appendix F, 32).

Although mothers with children aged 15 and over state that their caregiving intensity decreases as their children get older and that they provide support when needed, they still do not think of their children and their needs as entirely independent of their own support. In particular, the need to leave children completely alone at home and to be with their children in their life practices outside the home is even more evident. In this context, their support can be considered as limited, which means as needed, but sometimes continuing (AAIDD, 2002).

> So, when you look at it now, is she observed twenty-four hours a day in reality? She is being observed. … Since last summer, we started leaving her alone at home for half an hour. But we have a camera system, we control her with a camera (Mother 8, 15-year-old girl) (Appendix F, 33).

> I do not leave Child 9 alone; someone is usually at home together with her. She actually takes care of herself. But I am a little anxious mother. I do not leave her alone as much as possible. Usually, when something happens, the father stays home, and then I go, I wait, and then her father goes (Mother 9, 22-year-old girl) (Appendix F, 34).

> In fact, all children with Down syndrome, no matter how well they can be educated, no matter how good they are, live dependent on someone... This is the mother at first. You cannot leave them alone. No matter how good they are, these children are dependent on us. It's that simple (Mother 11, 24-year-old girl) (Appendix F, 35).

> I cannot leave her at home alone anyway. There is a market right next to our house. My neighbor also has a daughter with disability. She says, "Come there, let's go; the kids are sleeping anyway." And I say, "What if that my child wakes up? What if she cannot breathe if something happens..." … Child 12 is never left alone at home (Mother 12, 25-year-old girl) (Appendix F, 36).

> We live on the site, and everyone knows us. Child 14 is free within the boundaries that I consider safe, but other than that, she should never go outside this safe zone... Because she does not have any bad feelings inside, she thinks everyone is like that. There are all kinds of people, she can get

> harmed and I really cannot take that risk (Mother 14, 26-year-old girl) (Appendix F, 37).

From these mothers' statements, it is understood that their children need a certain level of support, albeit at different levels, during their adulthood, and the support of mothers exists in these processes. After learning the mothers' general evaluations about the intensity of care for their children, it would be more meaningful to examine their concerns about the future, future care plans and social policy expectations.

5.2 Mothers' concerns associated with the future of children with Down syndrome

In the next section, future care plans and social policy expectations of mothers regarding their children with disabilities would be shared as a result of interviews with 16 participating mothers. However, both in the literature and in the interviews, mothers talked about their concerns about the future of their children with disabilities. Concerns about the child's future, which form the basis of the current study, followed the first emotions felt and were expressed in different ways. As the general subject of the current study is that mothers have future care planning and social policy expectations for their children in a situation where they cannot continue to care for their children, they were evaluated by taking into consideration the themes of death and inability to continue caregiving.

> When something happens to a mother, the normal child is also left without a mother. But I have never experienced these thoughts with my other children. … but I have these concerns for Child 2 (Mother 2) (Appendix F, 38).

> These are the topics that really touch my heart. These are our biggest concerns as mothers who have children with disability. This is probably the main point of all mothers. So, I think like this: I do not want her to burden anyone. I always pray that she won't be left behind me, that she won't go before me. Anyway, I always dream of actually passing away on the same day. I hope we all have that kind of luck (Mother 4) (Appendix F, 39).

> I always think about what will happen if I die. It is the first question that comes to our mind after he born. I do not know; sometimes I cried a lot, wondering what would happen to Child 15 if I died (Mother 15) (Appendix F, 40).

In general, mothers have various concerns about the future of their children with intellectual disabilities in case of their own demise, and some of their evaluations are parallel to the literature. Also, parents may also tend not to plan for the future for a variety of reasons, although they do not deny the importance of making future plans for their children with intellectual disabilities (Engwall, 2017; Pryce et al., 2017; Taggart et al., 2012; Walker & Hutchinson, 2018; Walker & Walker, 1998).

Initially, future care planning can be emotionally challenging; thus, mothers may not prefer to talk about this issue. (Taggart et al., 2012; Walker & Walker, 1998).

> Actually, I do not want to talk about Child 1's future. Because when I think about Child 1's future, I become more worried. That's why I try not to think about it a bit, I guess (Mother 1) (Appendix F, 41).

> When I think about the future, I cannot get over it, so I try not to think about it anymore. I wish the best for all children (Mother 2) (Appendix F, 42).

> I cannot even talk about the future because it is painful. … When I talk about the future, my husband immediately tries to close the subject (Mother 16) (Appendix F, 43).

Also, as highlighted before, mothers may not be planning for the future because they may think it's too early concerning their young age (Engwall, 2017).

> Actually, I am not a person who likes to think about such bad things too much. As the events get closer, it seems more logical to take such precautions. So, thinking about ten years from now... Okay, of course, in my mind, I think about what will happen, but I do not know what will happen ten years from now. That's why it does not seem right to me to do something like that right now... As I said, maybe I think it's too early right now (Mother 14) (Appendix F, 44).

Additionally, some parents who had a strong faith and/or religion might not always discern the need for future planning, especially if they have a more fatalistic approach (Pryce et al., 2017).

> People do not know when death will come. But God knows first what happens after me... Only God knows what my child will do after me... May God give a good, long, and healthy life to the mothers who have children with disabilities (Mother 3) (Appendix F, 45).

> One cannot say anything about the future. Even if I kill myself, it is not what I say but what my God says (Mother 9) (Appendix F, 46).

> Well, actually, I have never thought about death... So, this is not something that can happen when I think about it; everyone has a destiny (Mother 14) (Appendix F, 47).

Also, these kinds of several excuses and/or reasons for not planning the future may stem from the parents' own family dynamics and characteristics, their own preferences or choices (Walker & Hutchinson, 2018).

> [Conversation between Mother 12 and her neighbor, who has a disability and only child] "What will be our children if something happens to us?" said my neighbor who has child with disability. "At least you have other children; yours will care for her, but who will care for mine?" She has only one child and worries. And I say, "Oh, are you thinking about these things now?" I just changed the topic (Mother 12) (Appendix F, 48).

Although mothers have difficulty talking about a future in which they cannot continue to care for their children with disabilities, this does not change their anxiety about the future of their children. As detailed in the following sections, they thought about various issues and sometimes took action regarding their children's future care plans.

5.3 Future care planning

Although it is not easy to plan or talk about future care, the mothers participating in the research are aware of the importance of future care planning and frequently express concerns about their children's future care processes. In parallel, there are

some prioritized issues regarding future care planning. These issues stand out mainly as financial issues and residential and housing issues.

Also, mothers participating in the current study think that their children's future care can be strengthened by the social support mechanisms they have established currently

> Currently, I stop every newly hired security guard, open Child 4's rear window, communicate with him and let him know her situation in some way, or when I catch him alone, I tell him. Because I do not know what will happen tomorrow. Therefore, we just have to plan the future from today. Now I have to plan today, too. How can you do not plan for the future? So, it's not possible (Mother 4) (Appendix F, 49).

> In fact, mothers need to build a support mechanism around them within their own means. I think this is also a future care plan. In other words, families need to start a future care plan while alive. How can they provide better opportunities for their children while they are alive? This can be done by using support mechanisms. It is necessary to be aware of the support mechanisms in the environment and to create them. So, I'm not saying this is easy. It's hard, but I think it can be done. It could be a neighbor; it could be the grocery store in the neighborhood. … When you look at it, we created our own support mechanisms together with my husband. Otherwise, none of these are support mechanisms provided by the state that come to us from somewhere else (Mother 8) (Appendix F, 50).

In parallel, developing social support mechanisms has been considered as a kind of future care planning that starts today. However, when it comes to future planning, the dominant themes are financial issues and residential and housing issues, and are detailed in the following sections.

5.3.1 Financial issues

As highlighted before, future care planning approaches are closely tied to family dynamics and can vary. When it comes to planning for the future care of children with intellectual disabilities financial issues come to the fore (Bigby, 1996; Coyle et al., 2014; Prosser, 1997; Taggart et al., 2012; Walker & Hutchinson, 2018). Make savings, leaving a real estate inheritance, relying on insurance inherited from parents,

and the child's own income and social security are among the prominent financial issues.

Seven of the mothers participating in the study clearly stated that they would make saving and leaving a real estate inheritance as part of future care planning for their children with DS. In addition, concerning financial issues for the future planning of children with DS, 6 of the mothers participating in the study highlighted the pension they would receive from the social security system. It is also noteworthy that mothers who do not refer to the social security system regarding financial issues in their future planning have family members with may not enough insured work background to entitle it (e.g. working without insurance, short-term employment background).

5.3.1.1 Make savings

In the context of financial issues, making savings on behalf of the child stands out as a plan for meeting the care-related needs of the child in the future and is parallel to the relevant literature.

> For example, I am going to the bazaar; I spend carefully... When my own father gives me money, I save it all for Child 5. Whatever I put financially, he can benefit from it. Some people have to live on the money they receive from cash-for-care for their children. That is why I'm thankful.
> Sometimes, we have money left over, and my husband says ‘’let’s save it for Child 5’’. These are really important (Mother 5) (Appendix F, 51).

> For example, a bank account... Child 11 will definitely have it. It will definitely happen Well, in terms of inheritance, there are some things she will get anyway. It will definitely happen, but of course, her legal guardian, for example, her brother, can be her legal guardian. If I die, her brother can manage this situation (Mother 11) (Appendix F, 52).

> Of course, there is an account that will cover a certain amount of financial things of her own. That, too, is something that will be under her sister's control. In this matter, as I said, think of it as a fund and let's think of it as a fund that will cover whatever is required regarding her care (Mother 14) (Appendix F, 53).

In some cases, it may be necessary for someone else to provide financial control for PwID. Care plans that include financial issues for children with intellectual disabilities with a certain level of disability may require the presence of a legal guardian to manage, and the mothers participating in this study were aware of this situation and envisaged their typically developing children as caretakers.

Similarly, in Turkey, PwID cannot open a bank account in their name without a legal guardian, which supports the fact that financial issues should be carried out entirely with someone else's support (Müberra & Özsoy, 2019). For example, Mother 9 encountered a related situation when she went to the bank to open a bank account on behalf of her daughter.

> In fact, her middle brother told me to go and open an account or her, let's save money etc... I went and could not do that either. When I asked for an account in her name... They said an account could not be opened in her name because she is disabled. I have not gone there again (Mother 9) (Appendix F, 54).

Overall, when it comes to future care planning, making and creating saving accounts that can meet the care needs of children with intellectual disabilities in the future and saving on their behalf comes to the fore. However, the necessity of the presence of a legal guardian is also appointed in these plans.

5.3.1.2 Leaving a real estate inheritance

Besides leaving children with intellectual disabilities a substantial amount of money (Bigby, 1996), giving their estate to their children with intellectual disability is the common option. In this study, some mothers' state that they have made/will make similar financial-related plans to meet their children's future care needs.

> For example, my husband is currently engaged in our own trade business. For instance, we bought a property for investment purposes for Child 1. My husband is saying that I purchased it on behalf of Child 1. So, this is his own security, money, and rental income. So, it's something that was bought

> entirely with that intention. That's why my husband thinks more about Child 1 in financial matters right now and has been working harder since his birth. How can he be more comfortable in future? How can he have an income, even without working, without needing anyone in the future? He's currently trying to do something entirely for Child 1 (Mother 1) (Appendix F, 55).
>
> In fact, the father says that there is only one house and it belongs to my daughter Child 9. Of course, I do not know what will happen if there are no parents (Mother 9) (Appendix F, 56).
>
> Of course, we have an idea that we should prepare something for the future; let's leave something like property to whoever takes care of him (Mother 15) (Appendix F, 57).

Real estate to be inherited finds its place in future care planning as a financial assurance with regular rental income or income from sales for the child. The income obtained from real estate has been evaluated as important in terms of ensuring the existence of the financial dimension to meet the care needs of the child.

5.3.1.3 Relying on insurance from parents

Moreover, related to financial issues, as mentioned in Chapter 3, there are schemes that can be directly or indirectly related to disability care in Turkey. Correspondingly, some mothers in the current study rely on the existence of various insurances to financially support. Especially, pensions are prominent in financial issues regarding future care planning.

> Let me say this for the situation where my husband and I have both passed away at the moment. Since we are both in different insurance types [the mother is a civil servant, and the father works in the private sector], we will both have salaries, a house and a car...We assume that they can care for Child 4 with two salaries (Mother 4) (Appendix F, 58).
>
> I do not know; we have private pension insurance, life insurance, etc. We are trying to do something that will make us financially comfortable… As I said, the only thing we have now is insurance (Mother 8) (Appendix F, 59).
>
> If something happens to us, Child 10 will get the benefit from his father's pension. I do not know, there is nothing else, I mean financially (Mother 10) (Appendix F, 60).

In this context, the pensions, which will come from parents' insurance are interpreted as future financial security for children. In fact, as Mother 10 states, it also stands out as the only financial security in cases where the family does not currently have any other savings or real estate that can provide a financial return.

5.3.1.4 Child's own income and social security

As mentioned before, Child 13, Child 15 and Child 16 are employed, and their income contributed to future care plans in several ways.

> I am already investing the money she earns in the bank. When she starts the work, our aim is that she can save money and manage herself as much as possible (Mother 13) (Appendix F, 61).

> So, if he retires, he will also have a pension. Child 15 has been working for ten years (Mother 15) (Appendix F, 62).

> The house was bought for Child 16. We bought this house from TOKİ [Turkey's government-backed housing agency]. Since we benefited from the disabled quota, the transactions were carried out on behalf of Child 16. We took advantage of the disabled quota but we paid the same amount of money. And then, we were paid the instalments for the house with Child 16's salary. Also, a lump sum of money had to be given. My husband withdrew cash from his pension, we are still paying (Mother 16) (Appendix F, 63).

Making various savings for the future with the child's salary, having his or her own pension, and contributing the child's salary to the purchase of real estate are stated as the main examples.

5.3.2 Residential and housing issues

Residential and housing issues stands out as one of the most important issues for mothers who live in the same house with their children throughout their lives, concerning future care. In parallel with the literature, the desire to live with children with disabilities for life was also emphasized within the scope of this study.

> I hope my God will allow us to live together until death (Mother 3) (Appendix F, 64).
>
> I want to be with him until the end, as long as my God allows (Mother 6) (Appendix F, 65).

Moreover, all mothers prefer their children to live at home and receive care in the future, albeit under different conditions. However, institutional care also stands out as an option in addition to home.

5.3.2.1 Home-based care

As stated, in the discourses of the mothers participating in the study regarding residential and housing issues, the preference for their children to continue to stay at home, in line with the literature, comes to the fore. Every mother who participated in the study insisted that they wanted home-based care for her child in the future, as it is now. However, preferences regarding whom the child can live with at home and under what conditions vary. In the context of the current study, the people who will provide home-based care and the conditions vary and can be listed as follows.

In detail, subheadings were started from their own home and potential caregivers within the family to receiving care from their own home but by a non-family member, and receiving care from a relative in their relative's home.

5.3.2.1.1 In the house of the family with the father

As stated before, in this study, the statements of mothers, one of the parents, on the subject were from their point of views. It is thought that if mothers cannot continue providing care for various reasons, children will continue to stay with their children's own fathers. Seven of the mothers participating in the study clearly stated that their children's fathers would continue to care for their children with DS in a situation

where they could not continue to provide care themselves. This situation was especially emphasized in the statements of mothers who are still married to the fathers of their children with DS.

> Apart from me, the only person who can fulfil this responsibility in a way relatively like me can be his father. I cannot see anyone else (Mother 2) (Appendix F, 66).

> I mean, if I am the only one who died, still, I am relief. So, in that case, I have no concerns. You know, the father will take care of her in every possible way, but of course, it will be difficult for him too (Mother 8) (Appendix F, 67).

> My husband does not leave his child if he is alive. I am sure. He won't leave her to anyone, even if he cannot do it Barrier-Free Life took us on holiday to Yalova before the pandemic. I saw a girl. I do not know her, but she dances, eats all the time and does something weird. I asked who the child's parent was. A man there said, "It's me"—a father. I said to her father you should stop your girl's overeating since they tend to gain weight so you cannot cope afterwards. My friend said that her mother is dead and her father does not know what to do. … My husband came to my mind. I said, one day, if I die, they would be Child 9 and my husband (Mother 9) (Appendix F, 68).

> Well, of course, since he is a boy, more of the burden falls on his father. Because he is a boy, it might have been difficult if it was a girl, but you know, I trust the father right now (Mother 10) (Appendix F, 69).

> Apart from me, who will take care of Child 16... A father will take care of him... I do not know; he has only a father and mother...We have no one else. But his father takes care of him (Mother 16) (Appendix F, 70).

Mothers predicted that their children could continue to stay with their fathers and receive home-based care from their fathers in mothers' absence. This situation brought about questioning this possibility, considering the presence of single mothers among the mothers participating in the study, because single mothers participating in this study emphasized that they did not have a future care plan that included the father of their children.

As a benefit of the semi-structured in-depth interview method, the question of what would change if the mothers who cared for their children were single mothers was asked, and the mothers' statements were taken. The presence of fathers is

emphasized both materially and spiritually.

> (In a situation where there was no father) I would have a hard time financially because if we put together the money for all the lessons we have taken so far, we would be able to build a road from here to the village... We had to receive special education with special methods since we could not go to rehabilitation centers during the COVID-19 period. If I were alone, I could not offer this quality of life to Child 4. I would still take care of her my own; she has already grown up. But I would have serious financial difficulties (Mother 4) (Appendix F, 71).

> Oh, it would be tough. A lot would change (if there were no father). So, first of all, it depends on two things: Do you have financial power or not? If I had the financial power, I would definitely have supporters, such as caregivers, teachers, etc. But it would only focus on caregiving if I did not have the financial power. So, there would be very few educational things in her life. You know, because when we look at Child 8's life right now, these are all things that come with financial items (Mother 8) (Appendix F, 72).

> I am a housewife. The father always worked. He left in the morning and came in the evening. He did not help in terms of taking care anyway, but... Otherwise, there was only the father for financial. Then, when cash-for-care came out, I did not need her father anymore (Mother 9) (Appendix F, 73).

The importance of the father's presence in the family was related to financial issues and the contributions that financial opportunities would provide to the child. Moreover, the spiritual importance of the presence of the father and husband figures in the marriage union has been expressed in many aspects.

> A lot would change if it weren't for my husband; I wouldn't exist either. While I was rocking the child, he supported my back, woke up at night, gave me water to drink, fed me, and said, "These days will pass, these days will pass." … My husband is behind me like a mountain; I cannot even imagine life without him (Mother 5) (Appendix F, 74).

> It would also be challenging emotionally. The support of a father, the support of a spouse, the support of a life partner for yourself... This is a very special thing. In general, if I give at least an example in my own life, I find it more challenging to be a single mother. My husband's help is essential (Mother 8) (Appendix F, 75).

Apart from this, there were also mothers who stated that their children's fathers did not provide enough support until the child reached a certain age or because he was working.

> My husband did not accept the child until he was 4-5 years old and could express himself. At that time, he was like as if he did not exist (Mother 7) (Appendix F, 76).
>
> If we had been in previous years, since he usually travelled domestically and abroad due to his job, the father's presence or absence was identical (Mother 13) (Appendix F, 77).

Still, in general, it is seen that mothers attach importance to the presence of fathers and prioritize the possibility that the children will continue to stay with their fathers in their own home settings and these are part of the future care planning.

5.3.2.1.2 In the house of a sibling with a sibling's family

As emphasized before, siblings have critical roles in the care processes of their siblings with disability (in this case, DS). In the absence of the mother, typically developing children play a critical role for children with disabilities, in financial issues as well as in planning care processes that include housing conditions.

Six of the mothers participating in the study assume that when they cannot continue to provide care, their children with DS will stay at the home settings of their siblings without disabilities and naturally with their families. However, it can be stated that siblings' gender is an essential variable in housing conditions and care issues.

> While I am alive, I would never want to give my other children a responsibility that will affect their lives like this, but if something happens to us, all the responsibility falls first to the brothers. So, in this case, his older brothers should protect him and take him to live with them (Mother 1) (Appendix F, 78).
>
> Absolutely, most probably, I would want him to live with his siblings rather than with someone else. You know, after parents, there are firstly siblings, of course (Mother 7) (Appendix F, 79).
>
> Who can I trust more than her brothers? Child 9 cannot stay alone... She can be with an older brother. For example, that person can use her father's pension, and he will take care of Child 9. I mean, I hope my God meet us, merciful daughter-in-law. So, the brother's wife is more important than the

> brother because she is a woman (Mother 9) (Appendix F, 80).
>
> We did not [talk], but the sister knows very well that we will entrust him to her and that she will take care of him. She knows very well that it is her duty. … Her sister can do this; I trust her. They can live together, and she will definitely take him with her (Mother 10) (Appendix F, 81).
>
> Having other boys and a daughter gives me confidence. All my children can take care of her. … My son said one day: "Child 12 is my sister; I would never leave her to anyone. I won't leave her to even my sister, brother. He made me very happy. I do not worry because she has brothers and sisters (Mother 12) (Appendix F, 82).
>
> Thank God her sisters also love her. I hope they will care for her after us. She will stay with her sisters, so I leave it like that for two or three days so that they can start taking responsibilities (Mother 13) (Appendix F, 83).

Accommodation of children with disabilities with typically developing children is among the options primarily considered by the mothers participating in the study. However, although it is generally known that PWID in Turkey generally receives care within the family, there is no accurate data on the number of adult siblings caring for their sibling with intellectual disabilities.

Generally speaking, in families where children with disabilities do not have siblings of the same gender, mothers tend to wish a typically developing child same gender with children with disabilities. For example, while mothers with a daughter with disabilities and typically developing sons wished they had a typically developing daughter rather than son. In parallel, mothers with a son with disabilities and typically developing daughters expressed that they wished to have a typically developing son.

> If someone was behind me and said, "I will help you’’; at that moment, I was thinking of another child. I would prefer my new child to be a boy, like my child with Down syndrome. I would consider one more, one more child (Mother 3) (She has a son with Down syndrome and two typically developing daughters)[5] (Appendix F, 84).

[5] To facilitate to understand of the section, Appendix 84-Appendix 87 includes information on the gender of the mother's child with Down syndrome and the number and gender of their typically developing children.

> … Sometimes I wished he had another brother. At least he would support him (Mother 6) (She has a son with Down syndrome and typically developing daughter) (Appendix F, 85).

> I wanted to have a daughter, but it did not happen. I immediately entered menopause as I was sad. … Sometimes mothers are afraid, so they prefer only one child. I am saying you are doing it wrong. Do not do this. Give birth to the second child; what will happen to that child without you? But it did not happen to me... I was praying, God, let me have a daughter and take care of Child 9 after me (Mother 9) (She has a daughter with Down syndrome and three typically developing son) (Appendix F, 86).

In addition, there is also a mother who stated that all her children are of the same gender, which is being a male, but she wishes to have a daughter. In this case, Mother 2 preferred having a daughter as potential to become second caregivers for her son with disability.

> When I look at the current generation, I cannot predict whether my 25-year-old son will live with us. But after Child 2, I wished I had a daughter who could approach Child 2 more compassionately and meet his needs... Or just for her to love him. … If I had a daughter, she care for Child 2 after I'm gone. But I cannot have such a dream about my sons right now. They want to declare their independence after the age of 18 and leave, but girls seem a little more motherly to me. But of course, I do not have a daughter, but I wish I did (Mother 2) (She has a son with Down syndrome and two typically developing sons) (Appendix F, 87).

It is clearly seen in these statements how much the expectations of families are affected by gender roles and how important this situation is for the lives of typically developing children (Aykara, 2015; Aykara, 2018).

On the other hand, in the statements of Mother 4, who has an only child and does not plan to have another child, she developed a critical approach to care planning made by relying on siblings.

> I would not have an alternative if I had a child older than Child 4. I would be a woman with two children, and since the second one had Down syndrome, I would organise my plan accordingly. … But there are so many people I know who gave birth so that a second child could take care of their child with disabilities. This makes me sad. I do not want to be born with such a burden. Why should my child be responsible for caring for her/his sibling? So, I would definitely make a plan. Whether I have a second child or not... It was

> not something I would want them to take care of their sister constantly (Mother 4) (Appendix F, 88).

However, in Mother 14, without denying that having a sibling with disabilities would impose a certain responsibility on the typically developing siblings, she stated that even if her first child were a child with a disability, she would consider having a second child in order to experience being the mother of a typically developing child.

> For example, those whose first child has Down syndrome usually have another child. I ask myself, when my first child is already disabled, did I want another child? I have a disabled child now, but as a mother, I would like to feel like having a typically developing child. Also, I think many people might think like that too… Because it is something different. But inevitably, there would be a responsibility on the typically developing child (Mother 14) (Appendix F, 89).

Mothers want to continue to care for their children with disabilities themselves as much as possible, and they are hesitant to attribute any care responsibilities to their typically developing children as long as they are alive. Overall, mothers have different evaluations of the involvement of their typically developing children in the care processes of their children with disabilities.

5.3.2.1.3 In the house of the family with another caregiver under siblings' control

Although siblings are one of the first people that come to mind, mothers may refrain from having their typically developing children assume all responsibility for their children with disabilities. Four mothers emphasized that if children with disabilities live in their own home setting with another caregiver, they prefer their children with disabilities to be under the close monitoring and supervision of typically developing siblings.

> May God introduce his sister to a good person. What is essential is not only her sister but also whom she will marry. He may seem very good, but I do not know if he will turn into a bad person after marriage... That's why, instead of

> entrusting my son to someone else, I want his sister to put cameras everywhere in his home setting. … My son can handle himself as much as he can, and he also would have another caregiver with him. … I will save up to hire a caregiver for my son at home without causing any trouble to his sister (Mother 5) (Appendix F, 90).

> Our main wish is for her to live in her own home setting and be cared there. … We have a plan like this: she should have a house and live there with someone, a caregiver. If you ask for a plan, there is such a plan. There will be a camera system at home and at work. Her sister will also visit and check on her (Mother 8) (Appendix F, 91).
> We talked about accommodation with Child 14's older sister. According to what she said, it's close to where her older sister lives, and it could be the same apartment building. That means living somewhere nearby, within reach. But not in the same home setting (Mother 14) (Appendix F, 92).

> He has a brother who can care for him, but we do not know whether the lady he will marry will care for him or not... But Child 15 can handle himself. I mean, Child 15, can only continue his life if there is someone who will keep an eye on him and see what is happening in his life (Mother 15) (Appendix F, 93).

As in the examples mentioned above, socioeconomic status is an important variable, especially in possible cases where the caregiver is not a family member. However, the socioeconomic status of mothers who wanted their children with disabilities to receive care from a paid person caregiver at home setting varied. For example, Mother 15, who received means-tested cash-for-care, deemed an accommodation that included such care processes appropriate for her child with DS, regardless of their socioeconomic status.

Still, the plan for a child with disability to receive care in his or her own home setting, where he or she had previously lived with his or her family, but with another caregiver and under the strict control of his or her siblings, appears as a plan that also includes certain accommodations.

5.3.2.1.4 In the house of the family with a publicly-funded caregiver

First of all, publicly-funded refers to financial support or resources that come from government sources or public funds. It means that the funding is provided by the government and is intended for the benefit or use of the public. Publicly- funded initiatives, programs, or services are typically financed by taxpayers' money and are meant to serve the public interest. A publicly-funded caregiver refers to an individual who provides caregiving services and is financially supported by public funds. In this context, the term implies that the caregiver's compensation or financial assistance comes from government programs or agencies rather than being privately funded (Yakerson, 2022).

In some cases, planning beyond family relationships is required for the child to continue living in the home setting. This option was emphasized by only 2 of the mothers: one did not have another child whom she could consider as a potential caregiver, and the other mother's typically developing child declared that she could not participate in the care of her sibling with a disability. For example, Mother 16's typically developing child stated that she would not take care of her sibling with a disability full-time for various reasons. For this reason, Mother 16, who wanted her son with a disability to continue receiving home-based care, stated that she preferred her son to live and receive care with a caregiver appointed by the state in his or her own home setting.

> I want home-based care for him. If no parents are around, I would like someone else to do the housework, care for his health, and stay with him (Mother 16).
> [So, would you like the state to appoint this person, or would you want it to be someone you know? (Researcher)]
> I wish the state would appoint... When people I know take care of him, who will control them? When the state appoints, at least it is done regularly and checked (Mother 16) (Appendix F, 94).

Moreover, Mother 4, who has an only child, stated that she wanted her daughter with DS to receive professional care at home and from people she could trust, in the future.

> Another alternative that comes to my mind is this: even if no one takes care of it, that money is still enough to hire a caregiver for Child 4. I wish there would be lovely aunts who will take care of her wholeheartedly. That would make me very happy... I would be happy if the government offered such an alternative, for example. If someone is assigned, her salary and insurance are paid... Her only job was to come to Child 4 every morning, spend the day together, and go home in the evening. I wish there were such an alternative (Mother 4) (Appendix F, 95).

In this context, the presence of a full-time caregiver in the child's home, appointed and monitored by the state, also came to the fore in matters related to accommodations when the topic comes to future care planning. The difference between the current section (In the house of the family, with publicly-funded caregiver) and the former section (In the house of the family, with another caregiver under siblings' control) is the emphasis on a publicly funded, controlled caregiver.

5.3.2.1.5 In the house of relatives with relatives

Another option considered by mothers who want their children to continue living at home is to have them stay with close relatives (Dillenburger & McKerr, 2011). Also, relatives may wish to be involved in the care that the PwD needs and receives (Koelewijn et al., 2023). More than half of the participating mothers mentioned this as an option.

> Our own family is too crowded. My husband's family has many uncles and aunts. So, who will take this responsibility when something happens to me? Probably, my husband's relatives will take this responsibility (Mother 1) (Appendix F, 96).

> We talked about this issue with our lawyer. We received the following feedback from him. We cannot leave a written document and say that my child will be handed over to this person after my death. First of all, the lawyer

> says, the government asks first-degree relatives one by one. As you know, this happens again through the court process. It starts with my brother. Does my brother want to take care of her? Will his economic situation be enough to take care of her? Or can he manage my money? The lawyer says the court evaluates the relatives one by one and gives her to the closest relative. Let's imagine I am not talking to my brother; I cannot say that I do not want my brother to take care of my child. We cannot make it official yet. We could not do anything right now. That was my priority I specifically wanted my own brother's wife's name to be mentioned because even if she broke up with my brother, she would not leave Child 4 (Mother 4) (Appendix F, 97).

> He also has an uncle and an aunt. I told them. His aunt and uncle are very compassionate. I tell them there is no one else (Mother 5).
> [Have you had such a conversation with his uncle or aunt? (Researcher)] Of course, after me, I said my son is entrusted to you (Mother 5).
> [What kind of answer did you get? (Researcher)]
> They say ‘’I would gladly do it’’ (Mother 5) (Appendix F, 98).

Living in the house of relatives, with relatives, is another future plan concerning their children expressed by mothers.

To sum up, participating mothers clearly stated that they desire their children to continue living in the home setting. Also, since they assume that their children cannot be completely alone, potential second caregivers are highlighted. In this case, it can be noticed that any process related to future care planning may differ according to the dynamics of the families and that a standard living condition cannot be stated. Still, mothers consider all potential people, including fathers, typically developing siblings, publicly-funded caregivers, and relatives as second caregivers so their children can continue receiving home-based care.

These conclusions align with earlier research indicating that families should designate a key person for the purpose of overseeing the fulfilment of the needs of children with intellectual disability to brace for the future (McConkey, 2005; Niedbalski, 2023).

5.3.2.2 Institutional care

Institutional care is considered by the mothers participating in this study as a form of accommodation that comes to the fore when home-based care is not possible and under certain conditions. Despite the widespread statements of mothers supporting home-based care for their children, some mothers consider that institutional care is at least an option and may be necessary in some cases.

5.3.2.2.1 General evaluations of institutional care

Mothers' general evaluations of institutional care as an alternative to home-based care tend not to be positive among mothers who wish their children to continue receiving care at home. Half of the mothers participating in the study made negative evaluations of institutional care as soon as they heard the name of institutional care.

> I do not know if I would send my child to places only for individuals with special needs... Again, I feel like I would like him to be with more normal people (Mother 1) (Appendix F, 99).

> I can say that we never, ever want institutional care. I do not know what I want, but I do know what I do not want. No institutional care (Mother 8) (Appendix F, 100).

> I do not even consider institutional care. In other words, they can take care of him at home. Well, I never thought about it until now (Mother 10) (Appendix F, 101).

> Wow, I was caught unready... Institutional care... She needs to be left all by herself if we are considering this option, God forbid. I do not want to think about it at all (Mother 11) (Appendix F, 102).

The general inadequacy and distrust of the care provided in institutions, including the social interactions, are the main reasons for disapproving of institutional care.

> So institutional care... Why do I reject institutional care? In other words, institutional care is a solution when people are truly helpless because institutional care is horrible. So, no matter what anyone says. If you ask the government, they provide very good care, but it is not. In addition,

> institutional care is places where there are no social activities and people are isolated, especially for people with disabilities. Not only people with Down syndrome but also people with physical disabilities have to live an isolated life (Mother 8) (Appendix F, 103).

> He was in a special class while enrolled in his first industrial vocational high school. There was a child who came from institutional care. He needed much love; he was in a bad condition. That's why I do not trust any institution, both private and state are the same. May God not let anyone fall (Mother 10) (Appendix F, 104).

> The government does it, but I do not know how caregivers will behave. In order to achieve this, education is a must. … You know, schools, houses where they can live comfortably should be built, but...The way the people working there treat them is important to me (Mother 10) (Appendix F, 105).

> There is no warmth in those institutions, there is no hugging… You know our children love of hugging… And there is trust, too. I do not trust (Mother 11) (Appendix F, 106).

When it comes to residential and housing issues and care, mothers who prefer their children to receive care primarily at home-based care consider institutional care as a last option when there are no other possibilities, and they think that it should at least exist as an option.

> In case the caregivers I planned were not looking after her, I prefer to have her be placed somewhere under state control, in a safe place. Because we have everything, we have the money to take care of her, but the child is in a situation where she cannot spend it without a legal guardian. Of course, it is always my priority for her to take home-based care in the environment she is used to. However, I am not prejudiced when it is necessary. If a social environment can be created where communication will not break down, and people will not withdraw into themselves, Child 4 will be pleased there. Child 4 will be happy there if she is not physically harmed or fed and if hygiene conditions are met (Mother 4) (Appendix F, 107).

> If his brother, parents, and siblings were alive, I would prefer him to be taken home-based care. But of course, if there is no one, institutional care would be better. The existence of institutional care gives confidence in cases when no one else can care (Mother 7) (Appendix F, 108).

> At least the existence of such institutions is nice, so it's nice to have them at least as an option. … It's better to at least there are than are not (Mother 9) (Appendix F, 109).

> Of course, I would prefer her to live at home setting if there is an opportunity. But let's say there is no opportunity; then, it is out of necessity. It's a

> necessary thing. I mean, it needs to exist [the institutional care]. … But it has to be above a certain standard. Each of them should have a separate room. I wish such a thing were possible. … It must be above a certain standard, even is publicly funded (Mother 14) (Appendix F, 110).

Thus, although institutional care is seen as a last option, discourses that support it being offered as an option if it meets a certain standard.

5.3.2.2.2 Situations where institutional care is considered by mothers

In some special cases, institutional care has been evaluated with a positive approach. For example, people with DS are at a higher risk of developing Alzheimer's disease as they age. This relationship is due to the presence of an extra copy of chromosome 21 in individuals with DS, which leads to overexpression of certain genes that are also implicated in Alzheimer's disease (Gomez et al., 2020). As a result of these genetic factors, individuals with DS have a significantly higher risk of developing Alzheimer's disease than the general population. It has been estimated that by age 40, nearly all individuals with DS may show signs of Alzheimer 's disease-related brain changes, and the risk continues to increase with age (Ballard et al., 2016; Bayen et al., 2018). Considering the advancing life expectancy, this may lead to different care needs of people with disabilities. Being aware of this situation, Mother 8 evaluated institutional care from this perspective.

> But in the meantime, I have to say this. As you know, the risk of developing Alzheimer's disease after the age of forty is very high in people with Down syndrome. I said "never institutional care", but in such a situation, if I am not alive, I would recommend institutional care to her sister. I mean, because it's tough. I see people with Alzheimer's all around me. After a while, home-based care is not possible. If there is a need for health care, bringing institutional care to the agenda may be an option. In other words, I will provide a safe environment for my typically developing daughter, to make that choice easily. ... Also, they may not be well financially after us... Her sister may be staying in institutional care as long as she follows her. This is life... In those aspects, I do not want to put such a burden on her. Everyone has to live his or her own life in some way. It's not easy to say this either. Of

> course, I also feel sorry for Child 8, but they are both my children. So there is nothing to do (Mother 8) (Appendix F, 111).

In cases such as Alzheimer's disease, which require different care needs, institutional care is considered reasonable because it can also include health care. Apart from these somehow positive examples and situations, other mothers participating in the study choice institutional care as a last option.

However, it is not possible to consider future care planning independently of social policy expectations. In the following section, the social policy expectations of the participating mothers would be emphasized.

5.4 Social policy expectations

Social policy expectations were also examined after exploring the approaches of the mothers participating in the study regarding future care planning. In social policy expectations, expectations regarding financial issues, and residential and housing issues for PwID, which are relevant issues in future care planning, as well as for future caregivers and other expectations, are also expressed.

5.4.1 Social policy expectations regarding financial issues for PwID

As stated in Chapter 3, where social assistance and services related to PwD are emphasized in Turkey, PwD can receive disability allowance if they meet various conditions. However, his approach results in insufficient coverage; thus, regular income given to a PwID as a cash transfer stands out in social policy expectations.

> I want my child to have a pension, which is small but still enough to support him (Mother 1) (Appendix F, 112).

> First of all, I really want her to get a disability allowance (Mother 11) (Appendix F, 113).

Moreover, it is expected that this cash transfer would not be cut even if the people with DS is working, and this request is justified by Mother 8 as follows.

> Firstly, people with intellectual disabilities, such as those with Down syndrome, must receive support from the state even when they work. Especially with age, there may be an increasing need for health expenses; they may have different needs, and it is impossible to cover them by working (Mother 8) (Appendix F, 114).

> If we are talking about their independence... It is not possible for people with disabilities to live at home with their caregiver in case they earn only one salary because these people can earn minimum wage or very little above it. In other words, whatever the lower level of that company policy is, they can work in those positions. They cannot work in higher positions, such as managers or general managers. In a different situation, if they are paid more than the minimum wage, their benefits may gradually decrease depending on their salary when they start working. Still, if they receive minimum wage, it should not be cut (Mother 8) (Appendix F, 115).

Additionally, as emphasized before, there are cash-for-care schemes in Turkey that are given to caregivers, not to the PwD themselves, and depends on the family's income. In this context, the importance of cash transfers to the person receiving care and determining entitlement based on the individual's own income, not the family income, were also emphasized.

> Social assistance should be determined according to the individual's own income, not the family income, and should be given to the individual. Cash-for-care must be given to people with disabilities, who must pay it to the caregiver they choose. Whatever happens. If they cannot do this, it will still be transferred to their account. The legal guardian can manage it, but it has to be like this (Mother 8) (Appendix F, 116).

In this way, receiving this cash transfer directly empowers PwD to have control over their financial resources. Furthermore, it promotes their autonomy and dignity. It acknowledges their right to make decisions about their own lives and use the benefits in ways that align with their personal needs, preferences, and goals. Otherwise, when benefits are given to family members on behalf of a PwD, it can inadvertently reinforce dependency and perpetuate the perception that the person with disability is incapable of managing their own affairs. Also, directly providing

benefits to the individual helps protect them from potential abuse or exploitation by others, including family members. This ensures that the cash transfers are used for the benefit of the person with disability rather than being mismanaged or misused, in general. This situation should be no different for PwID who may need legal guardian in financial issues.

Moreover, the pension from the parents' social security is considered a vital financial assurance concerning future care planning. Children with disabilities whose parents have died and who are found to have a disability rate of 60% or more and female children with disabilities who are at a rate below 60% are also granted 25% of this pension without any age limit (Turkish Down Syndrome Association, 2023).

However, male children with disabilities who are at a rate below 60% receive the same rate, maximum up to the age of 25 (depending on their education level) (Turkish Down Syndrome Association, 2023). However, this controversial situation, which applies to male children with intellectual disabilities, has been criticized especially concerning intellectual disability.

> Things like boys with intellectual disabilities not being able to receive their father's pension should not happen. Moreover, even if a legal guardian has not been appointed, they must be able to receive their parent's pension. I'm not saying money solves every problem, but I know that no problem can be solved without money (Mother 8) (Appendix F, 117).

In addition, as emphasized in the Chapter 3, it is possible to receive a pension from both parents in the social security system only in some cases. Concerning this, it has been among the social policy expectations that PwID receive a pension from both parents.

> After the parent's death, the child can only receive a salary from only the mother or the father. For example, these children should receive a double pension. … They should receive it whether they work or not, but their share may decrease depending on the salary they earn when they work. There should be no such thing as not taking it (Mother 8) (Appendix F, 118).

Receiving both parents' pensions can provide financial support and stability for their care and well-being.

Additionally, there are existing schemes' regulations as well as new social policy expectations regarding financial issues for the future care of PwID. For example, creating a pool of funds from a part of existing state deductions from the salaries of working parents with children with disabilities to be transferred for the future care of children has come forward.

> A fund can be created while parents who have children with disabilities are working. As payroll employees, we already pay forty to forty-five per cent of our income as payroll taxes. The government should not take a portion of its own. Also, the government should say, "I will also transfer twenty per cent of this to the fund I have allocated for the child with disabilities." It is the same with social insurance logic, but this will be a separate fund. The child will receive both a salary from me after my death and an additional salary from this fund. But these two should not cut each other; they should accumulate on each other (Mother 8) (Appendix F, 119).

In the financial issues section of future care planning, as stated by Mother 8 and Mother 10, families who do not currently have the opportunity to make separate savings rely on pensions from their own social security.

> We have things like private pension insurance, life insurance, etc. We are trying to do something that will make her financially comfortable… But as I said, the only thing we have now is insurance (Mother 8) (Appendix F, 120).

> His father's pension will go to him if something happens to us. After that, I do not know, I guess there is nothing else, I mean financially (Mother 10) (Appendix F, 121).

Similarly, creating a pool of funds to be used for the care of PwD after the death of one of the parents can be very functional, especially for families who do not have the opportunity to save for the future.

> So, let's say I cannot save money right now. At least, then I will save money for my child. The government will also pay twenty per cent of the income tax it collects. Maybe they will say, "Parents should contribute five per cent." If you already receive a monthly salary of 8,000 Turkish liras, the state also receives 8,000 Turkish liras from the employer. The government will say I am not taking my share; I am saving it for your child's future care. So, such a

> system needs to exist. Still, it is necessary to prevent the income and benefits of people with disability, especially people with intellectual disability, from being completely cut off. Because that income is not enough to live on, it is not enough to meet your needs (Mother 8) (Appendix F, 122).

Thus, the existence of cash transfers can be reassuring, especially for PwID, in a situation where cash transfers do not cut each other, where deserving one does not prevent deserving the other. It is possible to arrange in cases where minimum amounts are exceeded to a certain extent. However, it is expected not to be below the minimum income level.

5.4.2 Social policy expectations regarding residential and housing issues for PwID

Arranging accommodation and other necessary processes by making personalized care planning is one of the prominent social policy expectations within the scope of this study. It is recommended to create individual care plans for each individual, taking into account their different care needs.

> As you know, there is such a thing as the least restricted environment in the first stage, in education, and I think it should be the same in care. It is necessary to start from the least restrictive environment and progress, and it should also have a trial period. In other words, the person should first be cared for with appropriate support at home. If the failure is detected, the cause should be determined, and solutions should be produced by supporting the person again... In other words, the state will provide the necessary support, either alone at home or with someone. The state provided all the support and did everything, but it does not happen anymore. If the person requires being connected to a machine... Institutional care should be considered if she can no longer care at home. Maybe it could be if she needs to be under health monitoring; I do not know. But it shouldn't be like, 'We did this, we cannot provide home-based care for her; "Let's take her to institutional care." This should not happen (Mother 8) (Appendix F, 123).

As Mother 8 stated, it is recommended that the best practice to be planned individually to meet the person's care needs, should start from the least restricted environment.

Moreover, every mother participating in the study want that in a situation where she cannot continue to care for her child, her child's routine would be affected as little as possible, and she would continue to receive care at home. For this reason, there are an expectation that these people can be exempt from expenses such as rent and bills that constitute household expenses, especially in cases where there is no primary caregiver.

> Life support must definitely be provided in their own home. In other words, there needs to be support for these people, such as rental assistance and exemption for electricity and water bills. It will be exempt from natural gas, electricity and water bills. Then, okay, she can just get only her salary. But otherwise she definitely needs to earn additional income. It is not possible to provide the child's quality of life in any other way. And then there would be no need for institutional care. Then, care at home can be successful (Mother 8) (Appendix F, 124).

Covering home-based expenses as an accommodation support practice in one's own home is also considered to have the potential to enable the PwD to continue receiving home-based care.

In addition, it has been requested that services such as cleaning and cooking should be provided in accordance with the special needs of PwD who receive home-based care and whose primary caregiver is not alive, and regardless of their income status, based on demand.

> Child 13 does not like cleaning at all. Municipalities send house cleaning and cooking at home, but there are specific criteria there, too. You won't have a house, you won't have a salary, but actually, this is a ridiculous thing. They do not consider these needs physical or depend on ability, and they look at them financially (Mother 13) (Appendix F, 125).
> I want someone to do the chores and care for their health after me. Child 16 is gaining weight easily. I prepare meals suitable for his diet. Not everyone can do everything; I make his bread with wheat flour, etc (Mother 16) (Appendix F, 126).

However, although mothers want home-based care for their children to continue sustainably, almost every mother is concerned about how her child can socialise.

> As I mentioned, I prefer home-based care for her. I want it that she should not leave her regular environment. But, of course, socialization matters also worries me. So, will this child live at home alone? (Mother 4) (Appendix F, 127).
> This is actually something beyond care because when you say care, you only focus on providing care. Only the hygiene and cleanliness of the person, is he/she physically well? Does he/she eat his/her food, does he/she go to the toilet? That's what care is about So, there are also some emotional mental needs. What is that? Friendship, sociability, learning something. These are not included in institutional care. Yes, they are in theory, but they are not in practice. Cultural and social events, sports, etc., such as going to a shopping mall and drinking tea or coffee outside with her friends, should also be present (Mother 11) (Appendix F, 128).

Among the mothers who had concerns about their child being alone and not being able to socialise, Mother 1 suggested the foster family system, and Mother 8 suggested the personal assistant system.

> So, there is something that comes to my mind right now. I do not know if it will sound ridiculous, but I know there are foster families who want to adopt. I would like the same thing to happen to children with disabilities. I would like them to have a foster family, no matter how old they are, even if they are in an institution. This way, they won't be alone and at least socializing (Mother 1) (Appendix F, 129).

It has been evaluated that the PwD, who cannot continue to receive care from any family member, can socialize with their foster family in a situation where they receive institutional care, and foster family practice has been considered.

> When you say institutional care, there should not be large institutions; the largest should be like Hope Houses. But there is always a risk that they will return to small institution care. I do not remember which country it was in... For example, they closed all their institutions, and the institution no longer exists. There is no institutional care. Instead, they turned to tiny houses like the Hope Houses, but they say they are experiencing the same problems there as they do in institutions now. What's that? You know, isolation status, quality of care, transparency, etc. That's why they prefer a personal assistant system; they say the person should choose their own assistant, etc. So, of course, all of these systems may be open to abuse to some extent. Personal assistant may also be vulnerable to abuse. That's why I think it is essential that these are well-controlled. You know, being audited by independent auditors can be one thing (Mother 8) (Appendix F, 130).

As stated before, some mothers prefer for their child to live in the house of the family, with another caregiver under the control of a sibling.

> But we have a plan like this: she should have her own house and live there with someone, a caregiver; if you say a plan, there is such a plan. Her sister can control her from time to time. There will be a camera system at home and at work. Her sister will also visit and check her time to time (Mother 8) (Appendix F, 131).

> My son will have a caregiver with him so that he can manage himself. I would hire a caregiver at my own expense or publicly-funded. I would not hire a stranger. My God has not created anyone without a reason. His sister will have her family. I will save up to hire a caregiver for my son at home without causing any trouble to his sister (Mother 5) (Appendix F, 132).

> Child 15 can only continue his life if there is someone to keep an eye on him and see what is going on in his life (Mother 15) (Appendix F, 133).

In fact, this planning described by Mother 8 and other mothers in the subheading "In the house of the family with another caregiver under siblings' control" points to the personal assistant system.

A personal assistant for PwD is an individual who provides direct, one-on-one support to PwD, enabling them to achieve a range of activities and tasks. The role of a personal assistant is to support PwD in living the way they choose, taking into account their unique needs and preferences (Khasnabis et al., 2010). Personal assistants can be employed directly by the PwD or through an agency that specializes in providing personal assistance services.

Moreover, as detailed and discussed in the following sections, in the personal assistance system, PwD generally choose their caregivers themselves. However, when it comes to PwID, other people may be involved in the processes related to the personal assistant, and these people are usually parents. In fact, as Mother 5 stated, mothers may tend to choose familiar people who can care for their children other than themselves.

> The government should give me the money, so I can hire a caregiver. Even if I am not around, I want people I trust to enter and leave my house. The government cannot know what the caregiver's personality is like. For example, my aunt's daughter is in need. She is my aunt's daughter, so I know she is a good person. The state should give me money to hire a caregiver, and

> then I can hire her as a caregiver for my child. The state should cover it that way (Mother 5) (Appendix F, 134).

Although the personal assistant system is not implemented in Turkey, it is remarkable because it is an expectation pointed out in the current study. It has especially been evaluated and discussed in the section of ''Mothers' future care planning and social policy expectations in the context of Turkey.''

5.4.3 Social policy expectations regarding future caregivers

In cases where mothers cannot continue to care for their children with disability the caregivers should deserve a cash-for-care scheme in addition to the allowance received by the PwD is significant and among the expectations in terms of both continuing home-based care and providing financial security to future caregivers.

> I want my child to have a pension that can support him. Of course, I would like the person who cares for him to have cash-for-care. Unfortunately, as you can see in these living conditions, it is tough for an individual to get along financially (Mother 1) (Appendix F, 135).

> No one can simultaneously take responsibility and give money. It does not matter whether s/he is a relative; they must receive a payment (Mother 4) (Appendix F, 136).

Moreover, in addition to cash transfers, there is also an expectation that future caregivers should benefit from the same rights received by parents of children with disabilities.

> I really want cash-for-care to continue wherever he goes. The home in which he lives can benefit from it. Also, I pay half and half of my water bill right now, so let the others do the same. Whatever I benefit from, they should benefit from it, too (Mother 5) (Appendix F, 137).

> The caregiver does not necessarily need to be a parent, but should benefit from the same benefits as a parent. This could be early retirement or cash-for-care. It can be training, both the training the family can receive and the individual can receive. In fact, under normal circumstances, all kinds of support intended for parents should be extended to caregivers (Mother 8) (Appendix F, 138).

It is highlighted that future caregivers should be able to benefit from various rights that parents can benefit from.

5.4.4 Other social policy expectations

Beside expectations regarding financial issues and residential and housing issues for PwID, and their future caregivers as well as other expectations regarding health care are also highlighted.

In addition to being PwD, individuals may suffer from various health problems. However, although they can benefit from publicly funded health services, the fact that some costs are not covered or access to health care is not always easy creates various regulatory expectations.

> And they do not understand something; for example, they say that if it were typical, you would have to care... But there are different alternatives. While raising her more ordinarily, I would incur more ordinary expenses. Now, I'm spending three times as much instead. Her glasses are special, and we had to pay 1000 Turkish liras instead of 200 Turkish liras. They do not understand the difference (Mother 4) (Appendix F, 139).

> There are also costs that we cannot foresee. For example, glasses, even thinning the lenses, is a cost. Child 8's glasses are special, approximately 3000-5000 Turkish liras. All of these are costs. For example, she has scoliosis; I cannot take her to any publicly-funded hospital. You wait four to five years for dental treatment. So, it's not something that could happen. Therefore, at least for people with disabilities, or I am currently talking about Down syndrome and intellectual disabilities, there needs to be additional things such as unlimited access to these health services both in the private and public. Now, the state can decide whether to give cash or provide services. I look at the quality of the health service I receive. It does not matter whether I buy this with the money given by the state or whether the state pays the money for institutions, such as special education and rehabilitation centers. In fact, that second option may be much better because it may be better in terms of difficulties using money for people with intellectual disabilities. But they should still have their own earnings and maintain their home; I do not know, their caregiver should be able to choose and so on (Mother 8) (Appendix F, 140).

Mother 11, who suffers from disruptions in the provision of health services, also stated that she wishes there were special hospital departments for individuals with DS, especially in areas that individuals with DS frequently need.

> Ministry of Health needs to bring order... In other words, there are hospitals where the wait is much longer. I would like to have a separate department and a separate hospital for Down syndrome in Turkey. I really have such a dream. For example, a section of the hospital, three or four floors, which may be only for people with Down syndrome... Endocrine department, genetics department, orthopedic department, physiotherapy department... A Down syndrome hospital with these is something that should be (Mother 11) (Appendix F, 141).

Moreover, criticisms and expectations have been expressed regarding the medical disability report, which is indispensable for benefiting from various social assistance and services. Individuals and their families may benefit from services according to the disability rate specified in the report. In some cases, families may request that the medical disability report be prepared above a certain level in order to benefit from the services.

> The first report we received for Child 11 was 40%. Then, they increased it to 51% after I actually requested it to benefit from some things. Then I realized there was no need for this. I mean, nothing is right in this system. Nothing is right neither in education, health, the reports, or the system. Also, I am very angry that they put a percentage on children with Down syndrome and made them renew the report. Down syndrome is a genetic difference that will not change. For example, I shouldn't chase the 90% report to benefit from some things. Yes, my child is not 90%. But they shouldn't take our rights just because she is educated or talks somehow. Why should I be deprived of my current rights because my child is insufficient but not too insufficient? For example, this family needs a car since child with Down syndrome cannot travel on the bus or go somewhere alone (Mother 11) (Appendix F, 142).

> We wrote it as 70% in the disability report, but he is actually 50%. Child 15 does not receive cash-for-care because he works. We only use the disabled card, so public transportation is free of charge. Previously, there was a 50% seen in the report, and we could not benefit from this right. Only Child 15 could use transportation free of charge; I was paying for it. But he couldn't use public transformation without me anyway. Then, when disability rate increase to 70%, the person riding with you can now use the report free of charge. We also registered with TOKİ, but it did not work; we cannot buy a car, they want 95% disability (Mother 15) (Appendix F, 143).

As highlighted by Yılmaz (2014), since medical disability reports become a way of demanding rights, people tend to request reports with as high a disability rate as possible (Yılmaz, 2014).

In summary, expectations regarding cash transfers for PwID mainly are regular income for PwID (such as disability allowance), continuity of cash transfer regardless of employment, cash-for-care to the person receiving care and determining entitlement based on the individual's own income, not the family income, were also emphasized. Also, benefiting parents' social security regardless of the gender of PwID, receiving pensions from both parents (after the parent's death), creating a pool of funds from a part of existing state deductions from the salaries of working parents to be transferred for the future care of children with disability. In addition, pensions from their own social security are mentioned.

Furthermore, social policy expectations regarding accommodation for PwID are mentioned as personalized care planning for housing conditions, as little as possible affecting a child's routine. In addition, an exemption from household expenses came forward as potential to enable the PwD to continue receiving home-based care. In addition, demand-based life support, such as cleaning and cooking, is expected.

Moreover, the socialization of PwID is highlighted; moreover, the foster family system and the personal assistant system were suggested. Moreover, there is also an expectation that future caregivers should benefit from the same rights received by parents of children with disabilities.

Besides, other expectations regarding health care are also highlighted. Lastly, criticisms and expectations have been expressed regarding the medical disability

report, which is indispensable for benefiting from various social assistance and services.

Overall, Figure 2 demonstrates the thematic figure, which consists of a hierarchical coding of the findings, namely themes and subthemes in the current study.

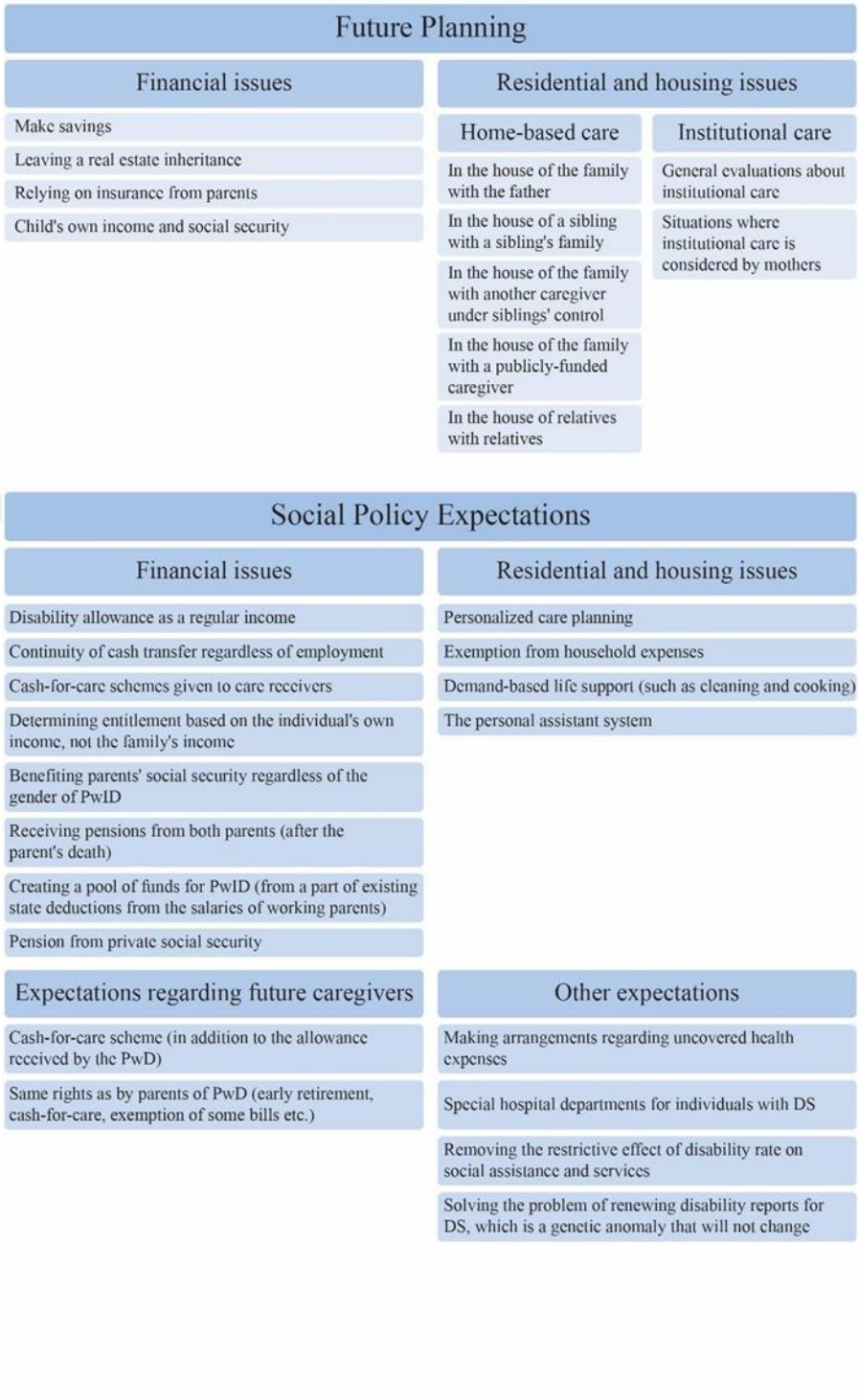


Figure 2. Themes and subthemes

CHAPTER 6

DISCUSSION

What happens to children with intellectual disabilities when mothers, who are the primary caregivers, cannot continue to care for them? What are the future care plans and social policy expectations of mothers who have cared for children with intellectual disabilities, specifically DS, throughout their lives for their children when they cannot continue to care? These are the main research questions that shaped the current study. In order to answer these questions, semi-structured in-depth interviews were conducted with 16 mothers of children with DS and their opinions regarding to the future care plans and social policy expectations were asked.

All in all, the findings were shown and discussed in this section with the related literature. This section also includes the strengths and limitations of the current study. Moreover, according to the results of the current study, the recommendations were provided for future researchers, especially in social policy.

6.1 Mothers' care needs evaluation of their children with Down syndrome and concerns associated with the future

The current study, which explores mothers' future care plans and social policy expectations for their children with DS, bears traces of the care support preferences that mothers will give to their children even when they are not alive.

The level of care required for children with DS can vary depending on various factors, including their mothers' perspectives and input. Within the scope of this study, the evaluation of children' care needs is discussed as an issue that may affect future care plans for their children if mothers cannot continue to provide care.

As a result, it is noticed that although the intensity of care given to children is affected by the age variable, mothers cannot imagine a fully independent life for their children, including adult children.

As children with DS age, the gap between the developmental processes of other peers widens, and differences in the mother's caregiving process may become more observable. Considering the mothers' evaluations, the intensity of care needs among children varies according to age groups, which does not always parallel to typically developing children. Mainly, levels of support range from intermittent (just occasional or “as needed” for specific activities), limited (as needed, but sometimes continuing), extensive (usually continuing), to pervasive (continuous in all realms of living) (AAIDD, 2002).

Many mothers wish to outlive their children with intellectual disabilities because they worry that their children may suffer from a reduced quality of life when they die (Aykara, 2015; Kruithof et al., 2021). Ideally, plans for future care and support should be formulated and communicated ahead of a crisis where decisions need to be made rapidly (Bibby, 2013; Walker & Hutchinson, 2017). However, although the importance of planning for the child's future, which forms the basis of the study, is not denied by mothers, talking about future care planning for a child with intellectual disability was considered a subject that is not easy to talk about.

Even the fact that mothers have difficulty talking about future care planning for their children indicates the need for intervention in the context of social policy, considering the possibility that the individual is unable to express their own views or has no independent advocate to do this on their behalf. Moreover, although planning the future care of children with intellectual disabilities is seen as a duty that can be attributed to families and the moral obligation can be imposed on families by society

regarding care (Prosser, 1997), such a vital and social issue should not be left solely to the initiative and possibilities of family members. Still, this common tendency of mothers does not contradict the fact that mothers have choices and/or preferences about what they want to happen to their children with intellectual disabilities (DS in this current study) after they cannot be continued care (Walker & Hutchinson, 2017).

6.2 Mothers' future care planning and social policy expectations concerning in Turkey

In this section of the current research, the findings on future care planning and social policy expectations of mothers with children with DS were evaluated in the context of Turkey.

Financial issues are among the prominent topics in both future care planning and social policy expectations. Regarding financial issues, families plan to make savings and leave real estate as an inheritance to meet the future care needs of children with DS. In other words, cash and cash-convertible resources are considered vital elements for future care for children with DS. However, plans such as making savings and leaving a real estate inheritance are entirely dependent on the family's financial means and are not possibilities that every family can offer for the future care planning of children with DS.

Moreover, even if families plan to make savings and leave a real estate inheritance for their children with DS, the PwID need legal representatives to use the existing financial savings. In other words, it requires other arrangements considering that PwID need legal representatives for expenditures related to care needs. In other words, although the importance of the existence of cash and/or cash-convertible resources is undeniable when it comes to future care planning, it cannot be

considered independent from other arrangements, such as the presence of a legal representative and can only be offered by families with certain economic power.

At this point, it is critical to evaluate social policy expectations regarding financial issues, to minimize the limitation that cash and/or convertible resources, which can only be provided by families with certain economic power.

Regarding social policies related to financial issues, having a disability pension for their children is among the relevant expectations of mothers. Mothers emphasized their expectation for their children to have a disability pension and expressed this as "engelli aylığı" in Turkish. However, although the concept is expressed as "pension" in the current practices in Turkey, it is not considered as a correct expression since it does not include contributions items. Within the scope of this study, the term disability allowance was used instead of disability pension in English, which mothers express as "engelli aylığı (disability pension)" in Turkish. According to the findings, disability allowance, which mothers refer to as disability pension, is one of the prominent expectations as it is considered a continuous and regular income.

However, among the findings of the study, a fund that is deducted from the salaries of working parents and will be created with the state contribution for the benefit of the child in the future is an approach that can be considered as a disability pension. Since the income criterion of the family is a critical determinant, especially for PwD to benefit from social assistance, people with relatively higher income levels cannot benefit from any social assistance. In this context, the creation of a fund that can be used in the future care processes for children with disabilities and providing a regular income to the PwD with the logic of disability pension as a

regular income can be considered as a more inclusive practice. In addition, this kind of approach allows going beyond the residual (for the neediest) approach for PwD.

The subheadings relying on insurance from parents and the child's own income and social security are elements of future care planning expressed in the context of financial issues. Moreover, there are various social policy expectations in the context of the social security system. As stated, mainly related expectations include sons being able to receive their deceased parents' pensions without age restrictions and receiving pensions from both parents. These expectations result from disability allowances being too low to provide a livable life. Since the disability allowances are too low to provide a livable life, the participating mothers suggested an arrangement for their children that does not interfere with each other and where deserving one does not prevent deserving the other, thus providing minimum living conditions.

It was detailed in Chapter 3 that social assistance to PwD in Turkey is subject to certain conditions. As a reminder, it is known that the relevant benefits are cut off in cases where the family's income increases or the PwD works with insurance. This situation is controversial in the context of both the fact that social assistance provided to PwD is affected by their family income, not their own economic situation, and that it negatively affects the participation of PwD in employment.

As focused on in this study, PwID may need social assistance even when working because, considering the nature of their work, they are likely to work for low wages and often have limited opportunities for advancement. In particular, the fact that families receiving social assistance know that social assistance will be cut off if their children start working and the disadvantaged position of the PwID at the point of sustaining his/her existence in employment may restrict the entry of PwID

into employment with the concern that the assistance will be cut off. The fact that employment is essential for full participation in life as well as material benefits makes this approach controversial.

In addition, people with DS may not be able to stay in employment long enough to retire because they age rapidly and usually start employment late. Some may have health deterioration that does not allow them to work full-time, and they may be working part-time. This situation may prevent them from accessing their retirement rights. Considering the subheading of a child's own income and social security, which stands out in financial issues in future care planning, it can be noticed that families care about regular income from the social security system. In this context, in the current study, it is necessary to make regulations by considering the situations mentioned in the regulations regarding the retirement rights of people with DS.

Moreover, the expectation that entitlement to social assistance should be determined according to the individual's own income rather than the family's income is also among the findings. In order to strengthen the independence of PwD, especially those who are adults, and to prevent loss of rights due to the variability of family income, the evaluation of the individual's status rather than the income status of the family at the point of allocation of social assistance was among the findings as a significant expectation.

Also related to the independency of PwD, although cash-for-care is a prominent scheme in the context of disability care in Turkey, contrary to similar practices, cash-for-care is not given to the care receiver, but to the family member who takes care of him/her is controversial in many respects. Firstly, from the perspective of care receivers, when cash-for-care is given to the family member who

takes care of him/her, it prevents the person with a disability from choosing the person who will meet their care needs (Serim & Akkan, 2022); this policy can actually be considered a violation regarding autonomy, which is highly regarded in liberal citizenship understanding. Also, being eligible for cash-for-care does not change the multidimensionality of the care needs of a person with a disability and the necessity of meeting them by different social institutions (Akkan, 2010). On the other hand, in countries like Turkey, where clientelist citizenship relations are dominant, the dynamics of charity culture can be felt in the way assistance is given. This fact feeds the citizenship paradigm, in which dependence on social assistance is imagined as a situation of shame (Akkan & Uyan-Semerci, 2014).

Giving cash-for-care payments to the caregiver rather than the care recipient is a controversial issue due to the different approaches to the development of relevant policies in Turkey. However, there are situations that involve special requirements when it comes to PwID, not limited to cash for care. It is noteworthy that in care plans that include financial issues for individuals with a certain level of intellectual disability, the presence of a legal guardian is required, and this person is directly considered as a typically developing sibling (if any).

PwID may have difficulty making complex decisions independently. Legal guardianship is necessary for PwID because it helps ensure their well-being, protection, and rights (National Council on Disability, 2019). Legal guardianship allows a designated individual, known as the guardian, to make decisions on behalf of the PwID, ensuring their best interests are considered. Intellectual disabilities may affect a person's ability to manage their finances effectively. A legal guardian can help oversee financial matters, ensuring that financial resources are managed appropriately and the person's needs are met (Harris, 2024; National Council on

Disability, 2019). Also, a legal guardian can advocate for their medical needs, make healthcare decisions, and ensure they receive appropriate medical care and support since PwID may require assistance with healthcare decisions (National Council on Disability, 2019).

In addition, PwID may be more vulnerable to exploitation and abuse (Eastgate, 2012). Legal guardianship provides an extra layer of protection, helping to safeguard their rights and prevent potential harm (Harris, 2024; National Council on Disability, 2019). It is important to note that guardianship should be considered carefully and implemented with the person's preferences and autonomy in mind.

Alternatives to guardianship should be explored to promote self-determination and maximize independence, such as supported decision-making and person-centred planning (National Council on Disability, 2019).

In the context of Turkey, it can be said that new structures, such as supported decision-making mechanisms, should be created in the decision-making processes regarding how PwID can use their own money, and another legal framework change regarding PwID is required.

Overall, social assistance schemes, which have an important place in social protection systems today, tend to cover certain groups within the eligibility framework (Van Oorschot & Roosma, 2017). Meanwhile, the eligibility framework and distinguishing deserving and underserving determines the limits of inclusion and exclusion in the context of social assistance (Serim & Akkan, 2022). According to the Regulation on Determination of Persons with Disability in Need of Care and Determination of Care Service Principles, the emphasis on means-tested and medical disability reports draws attention (ASHB, 2006).

The person who wants to benefit from such cash transfers and services must submit a statement and relevant documents regarding whether he/she or his/her family is subject to social security institutions and income status (Social Services and Child Protection Agency, 2016). Income criteria are the most important determinant of receiving cash transfers and related services, and the evaluation of neediness regarding income is controversial since based on households. Basically, in Turkey, there is a minimum wage policy, which is legally the lowest wage level that can be paid to workers; the income criteria for these schemes are based on the minimum wage. Accordingly, consideration should not exceed two-thirds of the net minimum wage when the household's total income is divided by the number of people residing there (ASHB, 2023b). The way in which social assistance is given based on means-tested determination and bureaucratic requirements require beneficiaries to show their poverty status constantly. This situation is both far from a rights-based approach, and compulsory proof of poverty leads to controversial areas regarding human dignity (Serim & Akkan, 2022). In this regard, the significance of providing cash transfers directly to the care receivers, in addition caregivers, and determining eligibility based on the individual's income, rather than the family's income, was underscored by mothers in the current study.

While the need to regularly show one's poverty is essential, being needy and poor as a stand-alone category does not guarantee access to social assistance. The concept of the deserving poor is often associated with the concept of dependency; when the situation of dependency emerges together with poverty, the status of the deserving poor arises. Besides being poor, the existence of dependency status determines the category of the deserving poor; in this perspective, being PwD is a status that individual in poverty who deserve social assistance. In a perspective

where the dependency status of the poor and the need for assistance arising from this situation determine the category of the deserving poor, the state of being PwD is a category that brings the poor to the category of the poor who deserves social assistance (Serim & Akkan, 2022). This situation is also reflected in the discourses of social assistance administrators; for example, the senior administrator responsible for social assistance stated that:

> The main feature of assistance for us is this: We do not provide assistance to people just because they are poor. If they are poor and plus feature, we provide assistance. For example, we give if they are poor plus they are old. If they are poor and disabled, we provide them (Serim & Akkan, 2022, p. 899).

Regarding accommodation, including care processes, the desire to live with children with disabilities for a lifetime is also emphasized in this study, in parallel with the literature. It confirms the findings from previous studies that family carers do not readily contemplate alternative placements for their relatives (McConkey, et al, 2006).

In a situation where this is not possible, in the house of the family, with the father; in the house of a sibling, with a sibling's family; in the house of the family, with another caregiver under the control of a sibling; in the house of the family, with publicly-funded caregiver; and in the house of relatives, with relatives options were mentioned regarding home-based care.

Considering the gender roles in Turkey and the caregiver role attributed to mothers within the family, it is quite striking that fathers are emphasized as secondary caregivers in this study. Seven of the mothers participating in the study clearly stated that fathers of the children with DS would continue to care them in a situation where they could not continue to provide care themselves. All mothers, who think that the fathers of their children with DS can continue to care, are married to the fathers of their children and live in the same house. In this case, the father's

caregiving motivation may be related to preserving the child's current routine may be related to the father's continued caregiving.

Still, this is a striking finding in the context of Turkey concerning gender and gender role. For example, in Saudi Arabia, the needs of families with children with DS from mothers' perspectives and in a cultural and religious context were investigated; as a result, the most important need was found to be financial or tangible support (Alabri, 2023). The reason for the focus on mothers was that, according to Saudi culture, mothers take care of the home and are responsible for the children. Also, the father's position in Saudi Arabia plays a supportive role, for example, providing support to meet the needs of the family rather than knowing the needs of the family (Alabri, 2023). The fact that mothers take care of the house and are responsible for the children and that the most important need is expressed as financial or tangible support (Alabri, 2023) are parallel findings in the context of Turkey. However, in Turkey's context, although the father's position plays a supportive role, such as providing support in meeting the needs of the family rather than knowing the needs of the family in general, different discourses have been developed in this study regarding a situation in which the mother cannot continue to provide care. In this study, it is thought that if mothers cannot continue providing care for various reasons, children will continue to stay with their fathers. This is the result of the other parent, the father, being highlighted as the caregiver as a result of the desire for care to continue at home in a situation where the primary caregiver, the mother, cannot continue to provide care. At this point, when it is necessary, the motivation and tendency to continue to care for a child with disabilities within the family and home environment may blur the sharp lines of gender roles regarding caregiving.

Also, siblings are highlighted as potential caregivers when the mother cannot continue to provide care. Although this is a situation parallel to the literature (Bigby, 1996; Heller & Caldwell, 2006; Orsmond & Seltzer, 2000), it is an approach that does not take into account the care crisis that siblings who undertake care may face. As a matter of fact, one of the reasons why mothers do not want to talk to their typically developing children about the future care plans of their children with disability may be that they ignore or do not want to face the gap between reality and ideal expectations. In this context, precautions to be offered by the state should be developed in the context of both social policies and social service provision regarding the possible care crisis that potential caregivers may face in cases where primary caregivers cannot continue to provide care.

Sub-headings "In the house of the family with another caregiver under siblings' control" and "In the house of the family with a publicly-funded caregiver" contain a direct social policy expectation for the continuation of home-based care. In this context, the role of the caregiver will not be directly attributed to potential family caregivers, and care will continue in the home with a publicly funded caregiver. In this sense, the planning, implementation and control of such a care model require the cooperation of both social policymakers and PwD and their relatives. Finally, when it comes to residential and housing issues in future care planning, the option of "in the house of relatives with relatives" can be considered as one of the options to ensure continuity of home-based care.

The mothers involved in this study view institutional care as an alternative option that becomes prominent when providing care at home is not feasible under specific circumstances. While many mothers express a preference for caring for their children at home, some acknowledge that institutional care could be a viable and, in

certain situations, a necessary option. Moreover, as expressed by mothers, the approach that considers institutional care as a last option is also reflected in relevant policies (Buğra & Keyder, 2006).

It is necessary to determine the negative characteristics of institutions that provide boarding services to PwD that cause individuals to distrust and make them think that the social services are inadequate. The importance of society's prejudices and pressure on this issue has emerged. Negative evaluations of organizations that provide boarding services to PwD reveal that individuals cannot actually benefit from methods through social assistance and services, and the inadequacy of social assistance and services to solve their problems (Aykara, 2015; Aykara, 2018).

Relevant practices in Turkey position care as a need belonging to the private sphere rather than the public sphere. In the liberal citizenship paradigm, where the assumption of the self-sufficient individual is dominant, dependence is problematized in the public sphere. In this context, since dependency relations and care need are incompatible with the dominant values of the public sphere: independence and self-sufficiency, care is positioned as a need belonging to the private sphere rather than the public sphere (Sennett, 2003).

On the other hand, citizenship is crucial for defining, interpreting and translating needs into rights (Lister, 2003); in this context, being a citizen is directly related to meeting the needs. The positioning of care as a private sphere need determines the citizenship experiences of both the people in need of care and the family members who care for them.

In a social structure where dependency relations such as care are not accepted as a value in the public sphere, it is not possible for individuals who are in a relationship of dependency to be equal citizens (Tronto et al., 2006). In this context,

it can be noticed that ‘’fragile citizenship’’ is experienced, which points to the problems related to transforming citizenship into capabilities and participating in society as active citizens, although the right to citizenship is given by the law (Akkan & Uyan-Semerci, 2014, pp. 164).

Fraser's (1989) "politics of needs interpretation" highlights the definition of needs confined to the private sphere in the public sphere. This understanding makes it possible to move the need for care, which is rendered invisible in the public sphere and located in the private sphere, from being a family matter to the public sphere and to be evaluated as a social policy matter here. In addition, the policy of needs interpretation is important as it reveals the necessity of including people with dependency relationships in the needs assessment processes (Fraser, 1989); it is possible to interpret it in the public domain by considering the needs of caregivers and care receivers. When care is freed from identification with the private sphere and family, it can be presented as a political ideal (Tronto, 1994). Therefore, what is lacking is a concept of citizenship which recognizes the importance of care for the society (Leira, 1990; Knijn & Kremer, 1997).

Moreover, the role of caregiver, identified with being a woman, further strengthens the role of caregivers in societies where the fulfilment of care needs is limited to the private sphere. As emphasized in the statements of some of the mothers participating in the study, it is noteworthy in the context of gender roles that when it comes to future care planning, daughters and/or brothers' female spouses are prioritized as caregivers.

Feminist literature questions the concept of an independent and self-sufficient individual imposed by liberal theory by putting forward the care ethic approach, which facilitates visible in the public sphere care, a devalued concept in the public

sphere (Held, 2006; Sevenhuijsen, 1998; Tronto, 1994; Tronto et al., 2006). Care ethics include care, trust, mutual consideration, and solidarity without excluding justice, equality, and individual rights (Held, 2006). This fitting together paves the way for care to be considered a basic concept for citizenship and to be constructed as a universal need for everyone (Williams, 2005). Moreover, when the importance of care and the moral quality of care practice is not sufficiently recognized, the effort of caregiver women and other caregivers in society will be deemed worthless. Thus, care which includes dependency relationships should not be limited to the private sphere (such as the home) (Tronto, 1994).

Actually, PwD are actually considered a deserving dependent group (Yılmaz, 2010); however, the issue that can be problematized is that this dependency is limited to the private sphere (Akkan & Uyan-Semerci, 2014). Moreover, the consideration of PwD as a deserving to be in the dependent group is not related to the context of citizenship rights but to evaluating schemes for PwD as charity comprised of pity and compassion (Bezmez & Yardımcı, 2010).

When it comes to social policy expectations regarding residential and housing issues, personalized care planning, exemption from household expenses, demand-based life support (such as cleaning and cooking), and the personal assistant system were some of the prominent titles.

Based on the findings individualized care comes fore as a social policy expectation concerning residential and housing issues. It is recommended to create individual care plans for each individual, taking into account their different care needs. While people with DS may have some commonalities, there are many other factors and concerns specific to each person, needing an individualized approach to care (De La Garza et al., 2023). Therefore, rather than making a care plan based on

the diagnosis and ignoring individual needs, it is essential to adopt a personalized approach, taking into account the well-being of the PwD in a way that will least affect the child's current routine, which is one of the findings of this study.

As can be noticed in the future care planning, residential and housing issues heading of the current study, plans vary even in plans where accommodation continues in the home setting. In this context, individual care planning should be prioritised, taking into account the child's well-being and under conditions where the current order is least affected.

Parents can also express their future care planning preferences for their children in writing, such as a letter of intent. A letter of intent can be considered as a non-legal document that captures critical family information and preferences for the future (Heller & Caldwell, 2006).

Heller (2006) attempted a peer support intervention among families to encourage future care planning; having a letter of intent, a non-legal document that captures critical family information and preferences for the future, was a condition of being a participating family. The intervention played a substantial role in families completing a letter of intent, taking action on residential planning, and establishing a special needs trust (Heller & Caldwell, 2006). However, in this study, only one mother enhanced this kind of plan.

> I have a letter of intent. You can do it through a notary and leave it in a place at home. There is no problem as long as it is signed. My own family knows about it, and the lawyer also knows about it. By the way, my husband also knows that this is our mutual decision. So, when you think logically and ask who will care for this child, the distinction between your relatives as caregivers and the husband's relatives disappears. We chose this person who could genuinely care for her in the healthiest way possible. We wrote the letter; we left that, too. Her potential caregiver also knows about it. We can write it because she already said it was okay. She is my brother's wife. I asked her, and she approved. We were able to leave it in writing because she said, "Of course, I'll care for her." (Mother 4) (Appendix F, 144).

In this way, Mother 4 made a plan in which she expressed in writing who and how she wanted to care for her daughter in cases, where she could not continue to provide care.

Also, there are an expectation that these people can be exempt from expenses such as rent and bills that constitute household expenses, especially in cases where there is no primary caregiver.

Such an approach can facilitate the continuation of home care in cases where the primary caregiver cannot continue to care, can protect the cash resources of the PwD, which may already be considered limited, and can eliminate the difficulties in controlling financial resources, especially for PwID.

In addition, the importance of evaluating the ability of PwD rather than their families' financial situation in terms of deservingness in terms of demand-based life support (such as cleaning, cooking) was emphasized. Providing demand-based life support to PwD can be seen as a factor that both supports their independent living and makes it easier for them to continue receiving care at home.

On the other hand, although mothers want home care for their children to continue sustainably, almost every mother is concerned about how her child can socialize. The foster family system and the personal assistant system were highlighted as a kind of solution. However, there are no regulations regarding the personal assistance system. At this point, highlighting the personal assistant system and its context, especially involving PwID, is necessary.

Personal assistance is defined as a human right in Article 19 of the UNCRPD. Article 19 requires states to ensure that citizens with disabilities have access to support services, including personal assistance necessary to support living and inclusion in the community (United Nations, 2006).

Personal assistance is characterized as an alternative way of organizing practical and personal help for PwD for assistance in their daily life. Personal assistance is an individualized, user-led service which enables PwD to live in their own homes and direct their own services. These services can be funded through various means, such as direct payments, where the PwD receives a budget to hire their own personal assistant, or through government programs that allocate funds for personal assistance services. Overall, personal assistants are vital in supporting PwD in their daily lives, promoting independence, and enabling them to participate fully in society (Khasnabis et al., 2010). In many ways, personal assistance is the leading symbol of how independent living can be realized in practice (Brennan et al., 2016; Nosek, 1991).

However, as personal assistance programs have developed and expanded in different countries, the eligibility criteria have broadened to encompass users who necessitate someone else to assume these responsibilities on their behalf. Askheim (2003) investigated the adaptation of personal assistance for PwID in Norway and the experiences with the arrangement for this target group. Other people than the user, as a rule, fill manager role of the service when the target group for personal assistance includes PwID. Continuing advocacy and support are crucial to enable those users to take advantage of personal assistance for individuals with intellectual disabilities (Askheim, 2003).

The parents of users play a pivotal role in personal assistance for individuals with intellectual disabilities; they frequently undertake management tasks and act as representatives for their children. Thus, ignoring or undervaluing the roles of parents' of PwD might be a risk (Shakespeare, 2000). In other words, parental responsibility

for arranging and managing personal assistance schemes is a consequence of the expansion to new user groups (Askheim, 2003).

Concerning the personal assistant system as future care planning, it is known that representatives for the Swedish cooperative developed a model that includes 'service guarantors.' A service guarantor is someone who knows the user well and has the task of ensuring that the user has control over the arrangement (Ja¨mlikhet, Assistants & Gemenskap [Equality, Assistance and Fellowship], 2024). A service guarantor teaches the assistants to interpret the user's communication signals. After hiring a personal assistant, the service guarantor collaborates with them during the initial phase until the personal assistant becomes familiar with the user (Ja¨mlikhet, Assistants & Gemenskap [Equality, Assistance and Fellowship], 2024). At this point, related to the current study, the primary caregiver (mother) can prepare the personal assistant, as a service guarantor, for the future care of her child before a situation in which she cannot continue to provide care. Or, as mothers also stated, in a situation where someone else is the caregiver, the role of typically developing siblings in the lives of siblings with disabilities can be shaped as a service guarantor. However, for all these, the personal assistant system should find a place in the context of Turkey.

As a matter of fact, this expectation was also expressed by the participating mother. It is known that one of the most important issues for individuals with DS is the maintenance of continuity in daily routines, especially in their later years. Thus, ensuring the continuity of daily routines would be essential in a situation with a personal assistant system, and the service guarantor can facilitate the continuity of daily routines (Covelli et al., 2017; Covelli et al., 2020).

Related research studies show that, in general, there do not seem to be any significant differences between the backgrounds of the personal assistants and the

employees in ordinary care services (Guldvik, 2014). Also, risks must be minimized for workers carrying out assistance within the structural framework of the personal assistance plan (Guldvik, 2014). It is very important to train personal assistants with formal qualifications and a health and social care background, especially in the context of social service provision and social policy expectations. Also, stability among personal assistants is vital, and supervision and guidance of personal assistants should not be neglected.

Additionally, expectations regarding future caregivers were expressed as another social policy expectation. It is crucial that caregivers should receive a cash-for-care as insured, in addition to the disability allowance received by PwD. This is seen as an important aspect of fulfilling expectations for both sustaining home care and ensuring financial stability for future caregivers.

Also, the fact that a significant majority of caregivers receiving cash-for-care are women (Akkan, 2010; Atasü-Topçuoğlu, 2021; Avşaroğlu, 2018) legitimizes the responsibility of women's care in the home settings and creates an obstacle to their participation in the formal labor market. On the other hand, the authorities express in their discourse that the cash-for-care given in return for caregiving is a wage given in return for women's care labor. However, despite this rhetoric, the demands of caregivers, who are appointed as if they are professional care personnel by legitimizing domestic care responsibility, to take place under social security and qualify for retirement have not been met. This situation creates the impression that caregiver women are engaged in the cheap, uninsured working class. The fact that the training of professional public employees who will provide home-based care services and the steps for these employees to work in this field are not included as a political choice can also strengthen this argument (Yılmaz, 2014).

Regardless of whether caregivers are parents or not, they are expected to have the same rights as parents of children with disabilities when they care for PwD; mainly early retirement, cash-for-care, and exemption of some bills are highlighted.

As highlighted before, people with DS may have various health problems such as heart defects, stomach and intestinal issues, immune system disorders, endocrine problems, obesity, spine problems, leukemia, dementia, dental problems, ear infections and hearing and vision problems (Baumer et al., 2023; Heinke et al., 2021).

Considering the widespread yet not covered publicly-funded health expenditures of people with DS and their healthcare needs, which tend to increase as they age, mothers' expectations regarding healthcare provision for their children with DS have also come to the fore. Also, it is known that private health insurances tend not to insure children with DS; therefore, they do not receive complementary support for their treatment (Grand National Assembly of Turkey [Türkiye Büyük Millet Meclisi], 2020; Milliyet, 2019).

In addition, long waiting times to get an appointment in public hospitals were also mentioned as another problem. As a solution to these problems, a hospital model where only people with DS can receive health services was proposed. Moreover, the demand for state-funded health services from private hospitals was expressed due to the waiting times in public hospitals and the fact that people with DS are not covered by private health insurance.

The validation of the reports can be temporary or indefinite, and the validity period of the disability report must be specified in the report (ASHB, 2019b). Based on the findings, removing the restrictive effect of disability rate on social assistance and services and solving the problem of renewing disability reports for DS, which is

a genetic anomaly that will not change, are remarkable social policy expectations related to health.

The medical disability report for PwD in Turkey is a document prepared by the delegations authorized by the Ministry of Health, which evaluates the disability status, disability groups, disability types and disability degrees of the people. Medical disability reports received are of two types: temporary and indefinite. A temporary medical disability report is given to people who are considered to have an improvement in the condition or a decrease in the severity of the condition and are expected to be updated on time (ASHB, 2023f). However, DS is a genetic difference that will not change, and the necessity of renewing the disability reports of people with DS at certain intervals without any situation affecting the disability report has been criticized.

Furthermore, disability calculation formulas that will create the disability report also have a determining factor in entitlement. In Turkey, since 2006, International Classification of Functioning, Disability and Health (ICF) has been the main classification tool for medical boards which are responsible for giving disability reports (World Health Organization [WHO], 2001; World Health Organization [WHO], 2011). Consequently, changes made in the calculation formula of disability occurred, leading to restrictions put on the eligibility of PwD for entitlements.

Moreover, related ministries implemented this new formula retrospectively to those who already had a medical report. Although the retrospective implementation of the new formula till 2006 was not legal, it caused a considerable number of PwD to no longer be eligible for disability rights which have before (Yılmaz, 2010).

Similarly, to benefit from some rights related to disability, specific statements about the level of disability should be expressed in ÇÖZGER reports; for example,

the mother's early retirement requirement depends on the child's severe disability. As is the case with PwD over the age of 18, the parallelism between the advanced level of disability and benefiting from rights is also seen here.

Furthermore, children under the age of 18 are covered by ÇÖZGER, and the special needs levels of children are determined without specifying the concept or rate of disability (Republic of Türkiye Ministry of Health [Türkiye Cumhuriyeti Sağlık Bakanlığı], 2023). In this context, a regulation should be made to cover ÇÖZGER for children under 18 and their relatives to benefit from rights (Grand National Assembly of Turkey [Türkiye Büyük Millet Meclisi], 2020).

Mothers who participated in the current study and expressed their expectations of social policy expressed their criticism regarding to the medical disability report, which is indispensable for benefiting from various social aid and services. In some cases, mothers are forced to request a medical disability report above a certain level in order to benefit from current practices. This situation not only pushes families to make not exactly true statements about their children's disabilities, but also has consequences that will reduce confidence in the fairness of the current practices.

Strict eligibility criteria that allocate rights to persons with disabilities based on disability rates facilitate limiting the financial burden of benefiting from these rights on the public budget. However, the PwD population is not only limited by those who apply for a medical disability report for access to the rights; but also, there are PwD who have experienced disability but have not been recorded with these reports. Therefore, it can be claimed that the coverage of the PwD population by social policies is quite limited (Yılmaz, 2010).

In the medical model, disability is considered a purely physical deficiency; it is directed towards treatment. However, the social model draws attention to the fact that disability is not only an individual/physical but also a social condition. In short, in the social model approach, disability is not a medical but a political issue (Yardımcı, 2015). Although persistent inequalities in the private spheres are generally invisible, the social model can challenge the distinction between public and private spheres (Morris, 1996).

In the context of the social model, although the importance and intensity of the studies carried out in Turkey for the independent and effective life of individuals with disabilities in society is considerable (Ünal, 2023); the social model approach may not yet be felt in practice.

In the medical model, disability or special needs have continued to be seen as a problem that needs to be treated (Yardımcı, 2015). In the current situation, it can be said that there is an approach closer to the medical model. The most remarkable indicator of this is that a disability report is required at certain levels in order to benefit from social assistance and services and to access educational diagnosis.

Mother 1, Mother 6, and Mother 11 learned that their child would have DS during prenatal screening tests. Although Mother 4 had a suspicion of DS before birth, she was certain after birth that her child had DS. In summary, the remaining 12 mothers learned that their child had DS after birth, usually by medical authorities. In this case, the majority of mothers in this study learned that their baby had DS after birth. There should be a diagnosis notification protocol for mothers who learn that their baby has DS after birth, and the doctors who make the diagnosis should inform the family in with a conscious approach. A protocol that specifies how the diagnosis will be communicated to families and a system to support families in this process can

minimize the impact of the information hierarchy between parents and doctors and reduce the likelihood of traumatization from the unexpected situation they face (Ulusal Down Sendromu Derneği, 2015; Mutlu, 2015).

The current study's findings were evaluated and discussed in the context of Turkey; by gaining a deeper insight into the viewpoints of caregivers, service providers will be better informed and better equipped to provide services that meet their needs (Hart & Neil, 2021).

6.3 Strengths of the study

The strengths of this study stem from its method and, in parallel, the original contributions of the participants. The qualitative research method and thematic analysis allow comprehensive results to be obtained through the power of in-depth interviews despite the small sample size. The fact that mothers with children with intellectual disabilities expressed their expectations regarding social policy through semi-structured, in-depth interviews also enabled the direct participation of the mothers in the production of knowledge on the relevant subject from the caregivers' perspective.

In addition, considering that there is no policy regulation regarding the care processes of PwID who have lost their caregivers, light has been shed on this dark area in terms of determining the needs of the individuals and providing them with effective approaches according to their special needs. Thus, this study looked beyond families' concerns and reached their future planning and social policy expectations, especially concerning mothers who have children with DS.

6.4 Limitations of the study

Several limitations should be considered in interpreting the results. In this study, mothers' own perspectives were examined for their children with disabilities. In this regard, mothers have found it difficult to talk about a period when they could not continue to care for their children. Considering that it is a very sensitive issue, some mothers felt the need to take a break during the interview, and it was observed that the mothers experienced emotional moments. Naturally, this was the most important limitation during the implementation of this study.

Another limitation of the current study was focusing only on those with DS within the umbrella concept of disability. Thus, its findings do not claim generalizability and representativeness to mothers who have children with disabilities. Moreover, since the subject requires subjective evaluations for each individual; it is hard to make generalizations.

Also, the study's sample size might not be big enough to fully profit from the nature of the qualitative method. The study was conducted with sixteen participants; still, some issues were reported by only one mother; for example, having a letter of intent. Moreover, the mothers' children's ages were between 2,5 and 35 years old, which may also be a limitation because there may be different planning and expectations for people over the age of 35.

As another limitation, some of the mothers interviewed were unfamiliar with the current social policy mechanisms regarding the issue of care. This situation may affect the social policy expectations of mothers who do not know about current practices.

Also, all participants were mothers. In other words, this study was limited to the perspectives of mothers of DS; however, every family member needs to be in the

process of future planning. It did not include the perspectives of fathers, siblings, or close relatives. Since fathers, siblings, and close relatives are prominent potential caregivers in this study, their contributions can also be very important.

It is also known that typically developing siblings report a lack of legal and financial knowledge when it comes to future planning for their siblings with disabilities, so it is very important to include people who may be involved in future planning. For example, siblings conveyed a sense of being unprepared, attributing it to a lack of knowledge about aspects such as guardianship, power of attorney, special needs trusts, and formal benefits (Rawson, 2010). Parents generally took charge of legal and financial matters, resulting in most siblings' limited involvement in these processes. This may also apply to other potential caregivers, such as fathers and close relatives.

In addition, since future planning should reflect person-centered planning, the voices of PwD are essential (Lee & Burke, 2020). Also, it is crucial that future care of PWID should be planned together when the current caregivers are alive. Since death is an abstract and complex concept, understanding death can be particularly difficult for PWID. However, PWID have a higher possibility of experiencing bereavement in current generations. Chow (2017) shows that PWID understand the concept of death partially or completely; the majority understand the fact that death is irreversible and the deceased no longer function (Chow, 2017). In this context, the lack of self-evaluation of PwD can also be considered a limitation.

In addition, when talking about social services and assistance that may be directly or indirectly related to disability care in Turkey, mainstream policies are highlighted, and local practices that do not have a national prevalence are not mentioned within the scope of the current study.

6.5 Recommendations for future research

More research is needed, considering the importance of future planning and social policies. This section presents recommendations for future research.

First of all, in this study, future planning and social policy expectations of mothers who have children with disability were explored. In this regard, it was recommended that future studies should examine PwD' needs directly from their own perspectives.

Additionally, family members such as fathers and siblings have critical roles in future care planning, and their perspectives should also be consulted.

In addition, it is very important to consult the relevant evaluations of authorities (for example, relevant ministry officials) and non-governmental institutions for future research, especially to evaluate future care plans based on applicable social policy.

In this study, only mothers with children with DS were interviewed. Another recommendation for future research was to investigate mothers' future planning and social policy expectations regarding different disability groups because future care planning and social policy expectations may differ depending on the type of disability. Different types of disabilities may require different care needs, differentiating future care planning and social policy expectations.

Also, the majority of studies featured limited sample sizes, predominantly consisting of white and female participants (Lee & Burke, 2020). Further research is necessary, specifically among diverse families, considering factors such as ethnicity, and socioeconomic status.

In addition, in this study, future care plans and social policy expectations are evaluated by taking into account the current practices in Turkey. A recommendation for future research is that different country examples with similar or different welfare systems can be examined with a comparative approach. In other words, research is needed to compare future planning across different countries since public policy may impact planning.

Lastly, this study revealed the future care planning and social policy expectations of mothers who continue to provide care. However, for future research, the ü post-parental care dynamics of PwD whose primary caregiver (mother) has passed away or who cannot continue to care can be explored.

6.6 Conclusion

When it comes to the issue of disability, it is clear that both care receivers and caregivers are a very diverse population in the context of care. It is vital to discover the future care plans and social policy expectations that mothers desire for their children when they are unable to continue providing care. Also, it is not possible to evaluate future care planning and social policy expectations independently of current practices and approaches regarding disability care in Turkey. In this context, future care planning and social policy expectations are noteworthy, especially regarding financial issues and residential and housing issues.

However, it is necessary to take into account the type of disability, degree, cause and many other possible variables in developing policies for the needs of PwD and their families. In the interventions that social policymakers will develop towards the problems and needs of PwID and their families, they should start directly from the feelings, thoughts and expectations of these individuals and their caregivers. In

addition, considering the structure of the society in which people live and their perspective on gender roles would increase the efficiency and functionality of policy implementations. Enhancing the comprehension of caregivers' experiences and requirements can enable policymakers and other stakeholders to provide meaningful support in fulfilling this crucial role.

APPENDIX A

SEMI-STRUCTURED INTERVIEW QUESTIONS (ENGLISH)

General Questions

1. How old are you now?
2. What is your marital status?
3. Are you together with your child's father? What is the age of your child's father?
4. How old were you when Y was born? Was your birth natural or C-section delivery?
5. How many children do you have? Can you tell their age?
6. What is your educational background?
7. Do you have any chronic disease?
8. What is your employment status? Have you worked before? (If she was working before, does her not working now have anything to do with his child?)
9. Where do you see yourself in terms of socio-economic status? (Such as lower, lower-middle, middle, upper-middle, upper class)

Care Experiences

10. Did you learn that Y was a child with special needs before or after birth? Can you tell me about the first time you learned it? What was your first feeling? What did you think about it?
11. Is Y a child who needs someone else's care/support/attention?

12. Who is responsible for Y's care? How would you define your own responsibility?

13. How many hours a day do you spend caring for Y? Do you need to observe s/he 24 hours a day or at regular intervals? Do you need to shape your own life/plans according to this care responsibility?

14. What is the disability rate as written in the medical health report? Are there any other accompanying diagnoses?

15. How is your child's day going? Is there a time during the day when s/he can be alone?

16. When you think about it, what are the care responsibilities you undertake for your child, what do you do for him/her in a day? If you were to arrange them in order of importance, how would you arrange them?

17. Is anyone/somewhere other than you responsible for Y's care? (If s/he has siblings) How is Y's relationship with his/her siblings? To what extent can they do the things you do regarding Y's care?

18. Do you think that Y being a boy/girl is an advantage/disadvantage in his current situation?

Future Care Planning

19. You mentioned your responsibility for Y's care. Who/who takes this responsibility when you do not fulfil this responsibility? How do you arrange it?

20. How do you feel about Y's care when you are not or cannot be for him/her? What do you think about his/her future care?

21. Do you have future care plans for Y? (If there is a plan, do you formalize it?)

22. Do you think planning for future care for Y is important? Why?

23. When you cannot provide care, what are your thoughts about the people who can care for Y (if any) fulfilling this responsibility?

24. If you were a mother raising your child alone, what would change regarding Y's care now and in the future?

25. Is anyone outside your nuclear family who will care for your child long-term? Who are they? Do they support you now?

26. (If she has another child) Would you prefer your other children to care for Y when you are not alive? What are your positive/negative considerations about this?

27. What are your feelings about the future of Y? Would the feelings you have just expressed change if Y were to work now or in the future? How?

Social Policy Expectations

28. In what environment and under what conditions would you prefer your child to receive care in the future?

29. Is there an association you are a member of? Is there any social assistance/service you benefit from? What services are you aware of that may be related to disability care?

30. If someone else were to care for your child after you in situations where you would not be responsible for their care in the future, what kind of services would you want these people and your child?

31. Do you currently benefit from a service that allows you to take time for yourself/take a break from your care responsibilities?

32. What are your knowledge and considerations about institutional care? If a suitable out-of-home alternative were available now or in the future, would you prefer your child to continue living at home? Under what conditions?

33. Do you think your child will be able to support you if you need care in your old age? (Can also be physical, emotional, etc.)

34. Can you talk about a disabled care service that would make you say, "If my child benefits from it, I feel at ease"?

35. Is there anything else you would like to add?

APPENDIX B

SEMI-STRUCTURED INTERVIEW QUESTIONS (TURKISH)

Genel Sorular

1. Şu an kaç yaşındasınız?
2. Medeni durumunuz nedir?
3. Çocuğunuzun babasıyla birlikte misiniz? Çocuğunuzun babasının yaşı nedir?
4. Y doğduğunda kaç yaşındaydınız? Doğumunuz doğal mı yoksa sezeryan mıydı?
5. Toplam kaç çocuğunuz var? Yaşlarını söyleyebilir misiniz?
6. Eğitim durumunuz nedir?
7. Bildiğiniz kronik bir rahatsızlığınız var mı?
8. Çalışma durumunuz nedir, daha önce çalıştınız mı? (Daha önce çalışıyorsa şu an çalışmamasının çocuğu ile ilgisi var mı?)
9. Sosyo-ekonomik durum olarak kendinizi nerede görüyorsunuz? (Alt, alt-orta, orta, üst-orta, üst sınıf gibi)

Bakım Deneyimleri

10. Y'nin özel gereksinimli bir çocuk olduğunu doğumdan önce mi öğrendiniz sonra mı? İlk öğrendiğiniz zamanı anlatır mısınız, ilk duygunuz ne oldu ne düşündünüz?
11. Y başkasının bakımına/desteğine/ilgisine ihtiyaç duyan bir çocuk mu?
12. Y'nin bakımından kimler sorumludur? Siz kendi sorumluluğunuzu nasıl tanımlarsınız?

13. Y'nin bakımına günde kaç saat ayırıyorsunuz? 24 saat gözetmeniz mi gerekir yoksa belirli aralıklarla mı? Kendi hayatınızı/planlarınızı bu bakım sorumluluğunuza göre mi şekillendirmeniz gerekiyor?

14. Sağlık raporunda yazan haliyle engel oranı nedir? Buna eşlik eden başka tanıları var mı?

15. Çocuğunuzun bir günü nasıl geçiyor. Gün içinde tek başına kalabildiği bir zaman dilimi olabiliyor mu?

16. Şöyle bir düşündüğünüzde çocuğunuz için üstlendiğiniz bakım sorumlulukları nelerdir, onun için bir gün içerisinde neler yapıyorsunuz? Bunları önem sırasına göre dizseniz nasıl dizerdiniz?

17. Sizden başka Y'nin bakımından sorumlu olan biri/ bir yer var mı? (eğer kardeşleri varsa) Y'nin kardeşleri ile ilişkileri nasıl? Onlar sizin Y'nin bakımı ile ilgili yaptığınız şeyleri yapabilirler mi/ne kadar yapamazlar?

18. Sizce Y'nin kız/erkek olması mevcut durumu özelinde bir avantaj mı/dezavantaj mı?

Gelecek Bakım Planlaması

19. Y'nin bakımına dair sorumluluğunuzdan bahsetmiştiniz. Siz bu sorumluluğu yerine getirmediğiniz zamanlarda kim/kimler bu sorumluluğu alır? Nasıl bir düzenleme yaparsınız?

20. Sizin olmadığınız ya da olamayacağız durumlarda Y'nin bakımı ile ilgili neler hissedersiniz? Neler düşünürsünüz?

21. Y için geleceğe yönelik bakım planlarınız var mı? (planı varsa; peki, resmileştirdiğiniz bir bakım planlaması var mı?)

22. Y için gelecek bakım planlaması yapmanın önemli olduğunu düşünüyor musunuz? Neden?

23. Sizin bakım sağlayamadığınız bir durumda sırasıyla (varlarsa) Y'nin bakımıyla ilgilenebilecek kişilerin (eşiniz, kardeşleri ya da başka birilerinin) bu sorumluluğu yerine getirmesiyle ilgili düşünceleriniz nelerdir?

24. Çocuğunuzu tek başına büyüten bir anne olsaydınız şu an ve gelecek için Y'nin bakımı ile ilgili neler değişirdi?

25. Çekirdek aileniz dışında çocuğunuzun bakımını uzun vadeli üstlenecek birileri var mı? Kimler bunlar? Şimdi size destek olabiliyorlar mı?

26. (başka çocuğu varsa) Sizin olmadığınız zamanlarda diğer çocuğunuzun Y'nin bakımını üstlenmesini tercih miydiniz? Bu konu ile ilgili olumlu/olumsuz değerlendirmeleriniz nelerdir?

27. Y'nin geleceğine dair duygularınız nelerdir? Y'nin şu an ya da gelecekte çalışması durumunda demin belirtmiş olduğunuz duygularda değişiklik olur muydu? Hangi yönde olurdu?

Sosyal Politika Beklentileri

28. İleride çocuğunuzun nasıl bir ortamda ve hangi şartlarda bakım almasını istersiniz?

29. Üye olduğunuz bir dernek var mı? Yararlandığınız bir sosyal yardım/hizmet mevcut mu/ hiç oldu mu? Engelli bakımı ile ilgili olabilecek hangi hizmetler bilginiz dâhilinde?

30. Gelecekte bakımından sorumlu olamayacağınız durumlarda (yaşlılık olabilir, hastalık olabilir) çocuğunuza sizden sonra yakınlarınızın bakım vereceği bir durum olsaydı bu kişilerin ve çocuğunuzun nasıl hizmetlerden yararlanmasını arzulardınız?

31. Şu an sizin kendinize vakit ayırmanızı /bakım sorumluluğunuza ara vermenizi sağlayan ve çocuğunuzla ilgilenildiği bir hizmetten yararlanıyor musunuz?

32. Kurumsal bakım ile ilgili bilgileriniz ve değerlendirmeleriniz nelerdir? Şimdi veya gelecekte uygun ev dışı bir alternatif mevcut olsaydı, çocuğunuzun evde yaşamaya devam etmesini tercih eder miydiniz? Hangi koşullarda?

33. Yaşlılığınızda bakım ihtiyacınız olması halinde çocuğunuzun size herhangi bir konuda destek sağlayabileceğini düşünüyor musunuz? (Fiziksel, duygusal vs. de olabilir)

34. ‘’Böyle bir hizmet/imkân olsa gözüm arkada hiç kalmaz’’ diyebileceğiniz bir engelli bakım hizmet sunumundan bahsedebilir misiniz?

35. Başka eklemek istediğiniz bir konu var mı?

APPENDIX C

ETHICS COMMITTEE APPROVAL

Evrak Tarih ve Sayısı:

T.C.
BOĞAZİÇİ ÜNİVERSİTESİ
SOSYAL VE BEŞERİ BİLİMLER YÜKSEK LİSANS VE DOKTORA TEZLERİ ETİK İNCELEME KOMİSYONU
TOPLANTI KARAR TUTANAĞI

Toplantı Sayısı : 38
Toplantı Tarihi : 21.12.2022
Toplantı Saati : 16:00
Toplantı Yeri : Zoom Sanal Toplantı
Bulunanlar :

Bulunmayanlar :

Buse Eren
Sosyal Politika

Sayın Araştırmacı,

"Future Care Planning and Social Policy Expectations of Families with Intellectually Disabled Children" başlıklı projeniz ile ilgili olarak yaptığınız SBB-EAK 2022/90 sayılı başvuru komisyonumuz tarafından 21 Aralık 2022 tarihli toplantıda incelenmiş ve uygun bulunmuştur.

Bu karar üyelerin toplantıya çevrimiçi olarak katılımı ve oy birliği ile alınmıştır. Onay mektubu üye ve raportör olarak tarafından toplantıya katılan bütün üyeler adına e-imzalanmıştır.

Saygılarımızla, bilgilerinizi rica ederiz.

Dr. Öğr. Üyesi

Öğretim Üyesi

e-imzalıdır
Dr. Öğr. Üyesi

Öğretim Üyesi
Raportör

SOBETİK 38 21.12.2022

Bu belge, güvenli elektronik imza ile imzalanmıştır.

APPENDIX D

INFORMED CONSENT FORM (ENGLISH)



BOGAZICI UNIVERSITY

SOCIAL POLICY MASTER PROGRAM

PARTICIPANT INFORMATION AND CONSENT FORM

Supporter Institution: Boğaziçi University

Research Name: Future Planning and Social Policy Expectations of Families with Children with Down Syndrome

Name of the Researcher: Buse Eren

E-mail:

Phone Number:

Research Advisor: Assoc. Prof. Zeynep Hande Sart

E-mail:

Phone Number:

Dear Participant,

Boğaziçi University Department of Social Policy faculty member Assoc. Prof. Z. Hande Sart and Social Policy Department Master's student Buse Eren are carrying out a scientific research project called "Future Care Planning and Social Policy Expectations of Families with Children with Down Syndrome."

Mothers with children with Down syndrome tend to have the responsibility of being their child's caregiver as much as possible. However, parents are likely to have concerns about the uncertainties their children may face if they cannot continue to provide care for various reasons. This research aims to explore parents' future care planning and social policy expectations regarding their children with intellectual disabilities.

Consent: As a parent of a child with Down syndrome, we invite you to participate in this research to discover what kind of future care planning you plan for your child and to learn your social policy expectations.

We would like to inform you about the research before your decision. Participating in this research is completely voluntary, and you will not be compensated or rewarded for your participation in the research. Within the scope of this research, we plan to conduct an interview using the semi-structured, in-depth interview method, which will last approximately 45-60 minutes. If you agree to participate in the research, we will interview you with 35 questions. You do not have to answer questions you do not want to answer.

All personal information, your name and contact information that you share with us during the interview will not be shared with anyone, and no information that can be attributed to your name or that will directly point to you will be included during the research or in the output of the research. If you consent to participate in this research, you have the right to withdraw from the research at any stage without giving any reason. If you change your mind after the interview and decide that you want to withdraw from the research, do not hesitate to get in touch with us.

Our interviews need to be audio recorded for your experiences and opinions to be accurately reflected in the research. While the audio recordings are transcribed, names and personal information will be anonymized and transcribed in order to protect confidentiality. Audio recording files and transcribed versions of the audio recordings will be destroyed after the work is completed. If you indicate that you give up contributing to the research, the interview records will be deleted and will not be used for future scientific studies. When you say you give up contributing to the research, you won't be negatively affected by this choice.

The research is expected to benefit society and academic studies in the context of disability and care policies in Turkey in the future. The research we want to conduct is not expected to pose any risk to you. If you deem it necessary, we can wait until you feel ready to answer the questions or take a break from the interview.

Considering that the interview contains some questions that may trigger emotions, it has been deemed appropriate to share with you the contact information of institutions that provide free psychological support. You can use the links below for more detailed information about the services.

- You can access the list of Healthy Life Centers that provide mental health consultancy under the General Directorate of Public Health within the Ministry of Health from the link below.

https://shm.saglik.gov.tr/shm-listesi.html

- You can apply to ALO 153 to benefit from the Psychological Counseling and Training services of İstanbul Metropolitan Municipality. You can click the link to get detailed information.

https://saglik.ibb.istanbul/psikoloji-danismanlik-merkezleri-pdm/

Please ask any questions you have about the study before signing this form. If you have questions later, you can ask the project manager and/or the researcher. You can consult The Ethics Committee for Master and PhD Theses in Social Sciences and Humanities regarding your research-related rights.

If your address and phone number change, we ask you to notify us.

I have read the above text and fully understand the scope and purpose of the study I have been asked to participate in. I had the opportunity to ask questions about the study and was adequately informed by the researcher. I agree to participate in the study voluntarily, and I consent to the recording of audio during the interview to be used for the benefit of the study.

I have (in this case, the researcher keeps this copy)/do not want to receive a copy of the form.

Participant Name:	Name of the Researcher: Buse Eren
Signature:	Signature:
Date (day/month/year):	Date (day/month/year):

APPENDIX E

INFORMED CONSENT FORM (TURKISH)

BOĞAZİÇİ ÜNİVERSİTESİ

SOSYAL POLİTİKA YÜKSEK LİSANS PROGRAMI

KATILIMCI BİLGİ ve ONAM FORMU

Araştırmayı destekleyen kurum: Boğaziçi Üniversitesi

Araştırmanın adı: Down Sendromlu Çocuğu Olan Ailelerin Gelecek Bakım Planlamaları ve Sosyal Politika Beklentileri

Araştırmacının adı: Buse Eren

E-mail adresi:

Telefonu:

Proje Yürütücüsü: Doç. Dr. Zeynep Hande Sart

E-mail adresi:

Telefonu:

Sayın Katılımcı,

Boğaziçi Üniversitesi Sosyal Politika Anabilim Dalı öğretim üyesi Doç. Dr. Z. Hande Sart ve Sosyal Politika Anabilim Dalı yüksek lisans öğrencisi Buse Eren tarafından "Future care planning and social policy expectations of families with children with Down syndrome/ Down sendromlu çocuğu olan ailelerin gelecek

bakım planlamaları ve sosyal politika beklentileri" adlı bilimsel bir araştırma projesi yürütülmektedir.

Down sendromlu çocuğa sahip olan ebeveynler çocuklarının bakım vereni olma sorumluluğunu olabildiğince sürdürme eğilimindedirler. Bununla birlikte ebeveynlerin çeşitli sebeplerle bakım vermeyi sürdürememeleri halinde çocuklarının karşılaşabilecekleri belirsizliklerle ilgili kaygılarının olması muhtemeldir. Bu araştırma ebeveynlerin Down sendromlu çocuklarıyla ilgili gelecek bakım planlamalarını ve sosyal politika beklentilerini keşfetmeyi amaçlamaktadır.

Onam: Down sendromlu bir çocuk ebeveyni olarak bakım vereni olduğunuz çocuğunuz için gelecekte nasıl bir bakım planlaması yaptığınızı/yapacağınızı keşfetmek ve sosyal politika beklentilerinizi öğrenmek adına sizi bu araştırmaya katılmaya davet ediyoruz.

Kararınızdan önce araştırma hakkında sizi bilgilendirmek isteriz. Bu araştırmaya katılmak tamamen isteğe bağlıdır ve çalışmaya katılımınız karşılığında size herhangi bir ücret veya ödül verilmeyecektir. Bu araştırma kapsamında yarı yapılandırılmış derinlemesine mülakat yöntemiyle yaklaşık 45-60 dakika arası sürecek olan bir görüşme gerçekleştirmeyi planlıyoruz. Araştırmaya katılmayı kabul ettiğiniz takdirde sizinle 35 soruluk bir mülakat gerçekleştireceğiz. Cevap vermek istemediğiniz soruları cevaplamak zorunda değilsiniz.

Mülakat sırasında bizimle paylaşacağınız tüm kişisel bilgiler, isminiz ve iletişim bilgileriniz herhangi biriyle paylaşılmayacak, araştırma sırasında ve araştırmanın çıktısında isminize atfedilebilecek ya da sizi doğrudan işaret edecek bir bilgiye hiçbir şekilde yer verilmeyecektir. Bu çalışmaya katılmaya onay verdiğiniz takdirde çalışmanın herhangi bir aşamasında, herhangi bir sebep göstermeden

çalışmadan çekilme hakkına sahipsiniz. Görüşme sonrasında fikrinizi değiştirir ve araştırmadan çekilmek istediğinize karar verirseniz lütfen bizimle bağlantıya geçiniz.

Aktardığınız deneyimlerin ve görüşlerin araştırmaya doğru yansıtılması için gerçekleştireceğimiz mülakatların ses kaydına alınmasına ihtiyaç duyulmaktadır. Ses kayıtları yazıya aktarılırken gizliliğin korunması açısından isimler ve kişisel bilgiler anonim hale getirilerek yazıya aktarılacaktır. Ses kayıt dosyaları ve ses kayıtlarının yazıya dökülmüş halleri çalışma tamamlandıktan sonra imha edilecektir. Çalışmaya katkı vermekten vazgeçtiğinizi belirttiğiniz takdirde görüşme kayıtları silinecektir ve yapılacak bilimsel çalışmalar için kullanılmayacaktır. Çalışmaya katkı vermekten vazgeçtiğinizi belirttiğinizde bu tercihinizin sizi olumsuz etkileyecek bir yaptırımı asla söz konusu değildir.

Araştırmanın ileride Türkiye'de engellilik ve bakım politikaları bağlamında topluma ve akademik çalışmalara yarar sağlaması beklenmektedir. Gerçekleştirmek istediğimiz araştırmanın size bir risk getirmesi beklenmemektedir. Gerekli gördüğünüz takdirde soruları cevaplamak için siz hazır hissedene kadar bekleyebiliriz ya da mülakata ara verebiliriz. Mülakatın duyguları tetikleyebilecek bazı sorular içerdiği dikkate alındığında ücretsiz psikolojik destek sağlayan kurumların iletişim bilgilerinin sizinle paylaşılması uygun görülmüştür. Hizmetlerle alakalı daha detaylı bilgi edinmek için aşağıdaki linklerden faydalanabilirsiniz.

- Sağlık Bakanlığı bünyesindeki Halk Sağlığı Genel Müdürlüğü'ne bağlı ruh sağlığı danışmanlığı sunan Sağlıklı Hayat Merkezleri listesine aşağıdaki linkten ulaşabilirsiniz.

https://shm.saglik.gov.tr/shm-listesi.html

• İstanbul Büyükşehir Belediyesi'nin sunduğu Psikolojik Danışmanlık ve Eğitim hizmetlerinden yararlanmak için ise ALO 153'e başvurabilirsiniz. Detaylı bilgi almak için linki tıklayabilirsiniz.

https://saglik.ibb.istanbul/psikolojik-danismanlik-merkezleri-pdm/

Bu formu imzalamadan önce çalışmayla ilgili sorularınız varsa lütfen sorun. Daha sonra sorunuz olursa proje yürütücüsüne ve/veya araştırmacıya sorabilirsiniz. Araştırmayla ilgili haklarınız konusunda Boğaziçi Üniversitesi Sosyal ve Beşeri Bilimler Yüksek Lisans ve Doktora Tezleri Etik İnceleme Komisyonu'na (SOBETİK) danışabilirsiniz.

Adres ve telefon numaranız değişirse bize haber vermenizi rica ederiz.

Yukarıdaki metni okudum, katılmam istenen çalışmanın kapsamını ve amacını tamamen anladım. Çalışma hakkında soru sorma imkânı buldum ve araştırmacı tarafından yeterince bilgilendirildim. Çalışmaya gönüllü olarak katılmayı kabul ediyorum ve gerçekleştirilecek mülakat sırasında çalışma yararına kullanılmak üzere ses kaydı alınmasına izin veriyorum.

Formun bir örneğini aldım / almak istemiyorum (bu durumda araştırmacı bu kopyayı saklar).

Katılımcı Adı-Soyadı:	Araştırmacının Adı-Soyadı: Buse Eren
İmzası:	İmzası:
Tarih (gün/ay/yıl):	Tarih (gün/ay/yıl):

APPENDIX F

QUOTATIONS (TURKISH)

1. Biz o gün şok olduk. Eşim daha çok şok oldu. Hatta böyle hiç konuşamadı. Yani o gün bir tek kelime dahi edemedi. Sonrasında ne olursa olsun bu çocuk bizim kabulümüz dedik ama yine de tabii doğana kadar böyle çok tereddütlüydük. Kendi kadın doğum doktorum yakın arkadaşım oluyor, bazı doktorlar %100 derler ama çocuk normal de olabilir demişti. Biz de yine normal olabileceğini umuyorduk ama açıkçası yani ben son ana kadar Down sendromlu olduğunu düşündüm (Anne 1 [Mother 1]).

2. Ben isme (Down sendromu) daha vakıftım çünkü çocuk gelişimi eğitimi almıştım. Hatta o çocuklara böyle ayrı bir özel bir ilgim vardı hem severdim hem de üzülürdüm. Bana yoğun bakımda olduğu için Down sendromlu olduğunu ilk başta söylemediler. Ama onu ilk gördüğümde ben anladım. Yoğun bakımdayken gidip gördüğümde ten rengi ve gözlerinden dolayı hemşireye sordum bebeğim Down sendromlu mu diye... Ben bunu kendim fark ettim, hiç bahsedilmemişti. … Sonrasında zaten yola başladık ama zordu. Hala da tabii ki zorlukları var. Ama tabi ki ilk duyduğumda zordu. Hangisi daha zordu bilmiyorum; kabullenmek mi zordu, annenin üzüntüsü mü? Çok karışıktı duygularım. Hala da öyle açıkçası (Anne 2 [Mother 2]).

3. Kolum kanadım kırıldı. Ne yemek yiyebildim, ne su içebildim. Şok olmuştum. 4 ay boyunca gözümün yaşı dinmedi. Ne zamanki bir hemşire geldi bana başka bir Down sendromlu çocuğu gösterdi, bak dedi senin çocuğun da bunun gibi olacak… O zaman gözümün yaşı dindi. Bu böyleyse ben neden ağlıyorum? … Eşim de tabii o da panikledi işte benim oğlum yok, buna baksın, çocuğuma kim bakacak ben ölürsem? Şimdi diyorum genciz biz. Sen ölürsen ben varım. Ben ölürsem sen varsın (Anne 3 [Mother 3]).

4. Eşim özel sektörde çalıştığı için bir devlet memuru olan benden daha iyi kazanıyor. Bunun artılarını da Çocuk 4'ün (Child 4) eğitiminde görüyoruz (Anne 4 [Mother 4]).

5. Kızımın ense kalınlığını ölçen ve ölçemeyen iki farklı doktor hikâyemiz var bizim. Doğru ölçen doktor, kendi doktoruma yani ölçemeyen doktora bu durumu iletmesine rağmen bize herhangi bir ek test yapılmadı bizim talebimize rağmen. … Yani öncesinde şüphe var. Aklımızın bir köşesinde Down var ama kesin net bilgiyle doğumdan sonra öğrenmiş olduk (Anne 4 [Mother 4]).

6. Daha önce hiç bilmiyordum. Hani görüyordum uzaktan o çocukları. İnsanın başına gelmeyince tam nedir, ne değildir bilemiyor. Bana söylemediler pat diye ama eşime söylemişler, çocuk yanıma gelmeden direkt eşim geldi. Eşime bir baktım bembeyaz olmuş. ''Ne oldu, bir şey var diğer çocuklar geldi benimki gelmedi ne oldu?'' dedim. ''Çocuğa yüzde seksen Down sendromlu diyorlar, Down sendromlu olunca engelli oluyorlarmış'' dedi. Yani o zaman ben çok böyle yıkıldım, ağladım, üzüldüm yani bu 6 ay sürdü diyebilirim. … Mahallemizde bir tane kadın benim

böyle doğum yaptığımı öğrenince hemen geldi ve bana dedi ki yürüyemeyecek, konuşamayacak. Bana yani o kadar çok kötü şeyler anlattı ki ekstra yıkıldım, mahvoldum. … Tabii çok üzüldüm ne olduğunu bilmediğim için (Anne 5 [Mother 5]).

7. Anne karnında dörtlü tarama testinde riskli çıktı ama nasıl olursa kabulümüzdür dedik. Dörtlü taramadan sonra bir şey yapmadık yani. Bekledik doğmasını. Zaten 36 haftalık doğdu. … Tabii üzülüyorsun Down sendromlu doğduğu için… Ama şok yaşamadık bekliyorduk olabilir diye. Allah'a şükür yani hiç böyle yıkım yaşamadım ama biraz tabii psikolojik olarak etkileniyorsunuz (Anne 6 [Mother 6]).

8. İkinci çocuğu Çocuk 6'ya (Child 6) destek olsun, gelişimini desteklesin diye istedik ve bilinçli olarak dünyaya getirdik. Çok da iyi oldu çok şükür. Ayrıca kız kardeşi Çocuk 6'ya (Child 6) hayat oldu bir yandan. Çocuk 6 (Child 6) tam pandemi döneminde lösemiye yakalandı. Tam 4 sene oldu işte ilik nakli oldu kız kardeşinden. Yani kız kardeşi ona can oldu o sırada (Anne 6 [Mother 6]).

9. Doğduğu an doktorun yüzü şaşkındı. ''Bu çocuk Down sendromlu'' dedi ve öylece tanışmış olduk Down sendromuyla. Çocuğum doğduğunda Down sendorumunun ne olduğunu bilmiyordum. Evet, görüyordum ama birebir temasım yoktu ve nasıl bir şey olduğunu bilmiyordum. Kaynım eğer böyle olduğunu bilseydik aldırırdık dedi orda işin çok ciddi olduğunu anlamıştım. Gerçekten önümde zor bir süreç olduğunu orada anlamıştım (Anne 7 [Mother 7]).

10. Ailemizin toplam geliri yüksek. Ama bu ancak ben ve eşim çalıştığı sürece sürdürülebilir. Yani birimizin çalışmadığı zamanlarda bu durumu sürdürme imkanımız yok (Anne 8 [Mother 8]).

11. İlk duyduğumda çok üzüldüm. Aynı zamanda hem endişelendik ve korktuk. Öncelikle Down sendromunun ne olduğunu bilmiyorduk, o yüzden bir korkumuz oldu. Nasıl bir şeyle karşı karşıya olduğumuzu bilmiyorduk. İkincisi hani çevremizden dışlanırız korkusu oldu. Üçüncüsü hep benim aklıma Yeşilçamlardaki köyün delisi figürü gelmişti ve onun ailesi falan… Böyle bir endişe hali, başarısızlık duygusu falan hepsi bir arada. Daha çok herhalde bu bir kâbus uyanınca geçecek şeklinde bir şeydi.
… Ama tabii ki hani o ilk duygu düşünceler içerisinde gelecekte ne olacak endişesi çok yoğun basıyordu. Yeni doğmuş bir bebek için ya biz ölürsek ne olacak korkusu… Yani her zaman yanında olup destek olacağımız kararı çabuk geliyor ama sonrasında belli bir süre duygusal iniş çıkışlar devam ediyor… … Yani ilk duygular her zaman bitmiyor, ara ara bazıları tekrar alevleniyor diyebilirim (Anne 8 [Mother 8]).

12. Benim için çok acı vericiydi. Şimdi iki doktor başıma dikildi. Akraba evliliği var mı, kaç yaşındasın, ailede engelli var mı diye sorular sordular. ''Benim kızım nerede? Ben kızımı görmek istiyorum'' dedim. Doktor da dedi ki senin kızın Down sendromlu doğdu. Yani hiç duymamıştım. Dedim ki o ne? Dedi ki resmen yüzüme ''senin kızın geri zekâlı'' dedi. Böyle söyledi. Psikolojim bozuldu, ben yerle bir oldum… Benim ağzım kilitlendi ve gözlerimden yaş akmaya başladı. Ben gözyaşımı engelleyemedim. Evet, engelli çocuklar olduğunu biliyorum ama Down sendromunu

hiç duymamıştım, ne olduğunu bilmiyordum. Adı da değişik hani, dedim ki o ne? O laftan sonra onun her anlattığı yüzüme bir tokat gibi geliyor. Öyle hissettim. Komşumun iki tane kız çocuğu vardı, ikisi de yatalaktı. O çocuklar gözümün önüne geldi.
Daha sonra bir üniversite hastanesinin genetik bölümüne gittik. Orada bir psikiyatrist vardı. Bize, "Kusur ne annede ne de babadaydı, sizin suçunuz yok. Bu Allah'ın size verdiği bir hediye" dedi. Bunu söylediğinde güneşim aniden yeniden doğdu. Yemin ederim karanlıkta yaşıyordum. Bir doktor güneşimi batırdı; başka bir doktor güneşimi çıkardı (Anne 9 [Mother 9]).

13. Test falan yaptırmadım. Doktorum test yaptırmam gerektiğini söylemedi, ben de yaptırmadım. Bilseydim yaptırırdım herhalde. İlk duyduğumda çevremizde Down sendromlu yoktu bir şok yaşadık. Kocam daha da şok olmuştu ama ben daha sakinim, daha metanetliydim. Onun Allah'ın bana bir hediyesi olduğunu anladığım için daha çabuk kabul ettim ve iyi ki oğlum var (Anne 10 [Mother 10]).

14. Ben üçlü tarama testi için kan verdim. Dönüşte de bir tane ‘’Bebeğim’’ dergisi aldım ve sayfaları çevirirken birden Down sendromlularla ilgili bir haber gördüm. Okumaya başladım, ilk defa orada tanıdım Down sendromluları. Merak da ediyordum hani bu çocuklar neden birbirlerine benziyor diye falan… Ondan sonra iki hafta sonra Down sendromlu olabileceği sonucu çıktı. Ben o ciddi şokla beraber farklı bir şey de yaşadım hani. Down sendromlu olabilir fakat bundan emin olamayız, amniyosentez gerekli dediler. Daha sonra kürtaj sürecini anlattılar. Bu beni çok ürküttü. Bunu doktor açık açık anlattığında zaten ben çoktan kararımı vermiştim. Sonra zaten Çocuk 11 (Child 11) yedi aylık doğdu, böyle bir hikâyesi var bu işin işte (Anne 11 [Mother 11]).

15. Kızımın iğnelerini yaptırıyorduk işte. O zaman doktor çocuğunuz "Mongol" dedi. ‘’Mongol ne demek doktor bey’’ dedim ben de. Önceden ne olduğunu bilmiyorduk... "Down sendromlu işte" dedi. Sonra babası sorular sordu, o zamanlar beraberdik babayla. Doktor böyle çocukların yarıdan çoğunun kalbi delik oluyor, Allah'a şükür sizinkisinde yok öyle bir şey dedi. Ama ileride bir sorun olur Allah bilir dedi. Her gün şükredeceksiniz dedi. Merak etmeyin her gün bir kelime öğrenecek... Gerçekten de adam biliyormuş, gerçekten de her gün bir kelime öğrendi (Anne 12 [Mother 12]).

16. Doktor hızlı hızlı geçiştirince hemşireye sordum ne demek istedi diye, o da zeka geriliği olabilir dedi. Sonra tabii ki üzüldük ve hemen ne yapabileceğimi düşünmeye başladım. O zamana kadar Down sendromu nedir bilmiyordum. Eskiden hepsini aynı kefeye koyarlardı; otistikmiş, Down sendromluymuş pek bilinmezdi. Şimdi tabii daha bilinçli insanlar (Anne 13 [Mother 13]).

17. Doğduktan sonra öğrendik Down sendromlu olduğunu, doğmadan önce bütün testleri yaptırmıştık, hiçbir şey çıkmamıştı. … Sonra doğar doğmaz fark etmişler, ben ayılırken sesler duydum kan alın götürün falan filan gibilerden. Sonra zaten işte eşim söyledi bana. … Tabii ben o anda hayatımın en büyük şokunu yaşadım. Bilmiyorum yani, hayatımda daha önce yaşamadığım bir andı. . Büyük kızımla ikinci çocuğumun aralarında yaş farkı az, arkadaş olurlar diye düşünmüştük. Fakat acaba ablasının üstüne yük mü olacak? İlk düşüncem buydu. Çünkü o zamana kadar Down sendromuyla ilgili açıkçası bilgim yoktu… Etrafımda tek tek görüyordum fakat

Çocuk 14 (Child 14) doğduktan sonra çok daha fazla görmeye başladım. Yani o zamana kadar çok bir farkındalığım yoktu açıkçası.
Doğduktan on, on beş gün sonra bir üniversite hastanesinde doktora götürdük. Bana sizin başka çocuğunuz var mı diye sordu, evet var dedim. Tamam, siz Down sendromlu olan çocuğu unutun, bir tane daha yapın çünkü hiçbir şey olmaz bundan dedi. Hiç boşuna emek vermeyin dedi bana ya. Ve ben zaten ondan sonra o kadar hırslandım ki... Yani ve gerçekten nefret… Ve ailemde babam dâhil bir sürü doktor olmasına rağmen doktorlara karşı içimde böyle bir olumsuzluk oluştu (Anne 14 [Mother 14]).

18. Doğduktan sonra ilk aşıya gittiğim zaman çocuk doktoru avucunun içine baktı ve ‘’bu çocuğu bir üniversite hastanesine götürün’’ dedi. ‘’Neyi var?’’ dediğimde engelli olabilir dedi. Tabii ben de o an ağlamaya başladım. Üniversite hastanesinde testler falan yapıldı, sonra doktor bana bunların eğitilecek çocuklar olduğunu söyledi, nasıl kediler köpekler eğitiliyor… Sen de eğitim verirsen topluma kazandırabilirsin dedi (Anne 15 [Mother 15]).

19. Bir devlet hastanesinde doğum yaptım. Çocuğum doğduğu anda asistanlar hemen bana çocuğunuz özürlü ve hiçbir zaman normal bir çocuk olmayacak dedi. Bana böyle dedi doktorlar. Ben hemen bayılmışım orada zaten kendimden geçmişim. Sonra işte doktordan doktora işte her yere gidiyoruz. … Sonra en son bir doktora gittik. Siz çocuğu oradan oraya, doktordan doktora gezdirmeyin dedi. Bu çocuğa iyi gelecek tek şey eğitimdir dedi. Eğitim. … Sonrasında eğitimlere katılmaya başladım ve onu nerede eğitim varsa hep götürdüm (Anne 16 [Mother 16]).

20. Tek başına çaresizdir yani, ben bırakamam. O yüzden sen dedin ya dışarıya gel, gelemem. Bu küçük kız evde olacak ama Çocuk 3’ü (Child 3) ona bırakırsam ya o oyuna moyuna dalarsa ve Çocuk 3(Child 3) kendine zarar verirse ben ne yaparım? Büyük [kız kardeşi] olsa bırakırım çünkü onun gözü sürekli üstünde. Bir yere gitse hemen arkasından gider. Ama küçük kızım ben bir de ona mı bakacağım diyor (Anne 3 [Mother 3]).

21. Dürüst olmak gerekirse zihinsel olarak pek bir değişiklik görmüyorum. Çünkü Çocuk 1 (Child 1) çok anlaşılır bir bebek, bizi hiç yormayan bir bebek. … Ama bir fark olması lazım derseniz, diğer çocuklarımın iki yaşında olduğu zaman ile Çocuk 1'in (Child 1) iki yaşında olduğu zaman arasındaki tek fark sanırım şu anda yürüyemiyor olması. Çünkü genel olarak algıları çok açık bir çocuk. Elbette gelecekte daha iyi, kendi ayakları üzerinde durabilen biri olabilmesi için elimizden gelen tüm eğitimleri vermeye çalışıyoruz. (Diğer çocuklarımla karşılaştırdığım zaman) farklılaşan şey üçüncü, dördüncü aydan itibaren fizik tedavi, eğitim gibi süreçlerin başlaması oldu (Anne 1 [Mother 1], 2 yaşında erkek).

22. Çocuk 2’nin (Child 2) diğer çocuklarınızdan ne farkı var derseniz benim için o yüzündeki benzerlik, bir de eğitime gidiyor olmamız Bunların dışında diğer çocuklarımdan hiçbir farkı yok. Hani uykusu olsun, öbür türlü özellikleri olsun diğer çocuklarımla aynı. Ama diğer çocuklarım onun yaşında bebek bezi kullanmıyordu ve tuvalet eğitimi almışlardı. Artı bir de tabii ki de kelime haznesi olarak daha geniş bir hazneleri var. O eksikliğimiz de var tabii ama onun dışında normal bebek gibi. Yani huzur açısından, uyku açısından, abileri ile anlaşması açısından diğer çocuklardan aman aman bir farkı yok. (Anne 2 [Mother 2]), 2,5 yaşında erkek)

23. Bizimki mesela kendini ifade edemiyor, su istemiyor. Altını değiştiriyorum. Biz buna yediriyoruz, yemek şey yapıyoruz biz ona veriyoruz. Tek başına kalınca balkonun kapısını açar, ne varsa atar. … Korkuyorum kendini de atacak. Camı açamıyoruz biz. Biri yanında olduğu zaman bakıyoruz, açıyoruz. Bir de kendine zarar, bir şey umurumda değil kendine zarar. Tek başına çaresizdir yani, ben bırakamam (Anne 3 [Mother 3], 6 yaşında erkek).

24. Şu an ilkokula gidiyor ve ben onunla birlikte gidiyorum. Kaynaştırma öğrencisi olmasına rağmen okulda tek başına kalabileceğine inanmıyorum çünkü. O nedenle güvenlik gereği, temel bakım ihtiyaçları gereği ben de onunla beraber okulda bekliyorum. Onun okul zamanında, ders saatlerinde ben de okulun çay ocağında bekliyorum. Teneffüslerde beraberiz. Yani bırakacak kimsem yok; o yüzden de sabah ben onunla okula gidiyorum, akşam o benimle okula geliyor [anne kamuda öğretmen].
İki buçuğa kadar onun okulundayım. Benim derslerim üç buçukta başlıyor. Bu kez o benimle benim okuluma geliyor. Benim derslerime hep beraber giriyoruz. Yine kendi dersime aldığımda da gözetlerim. Sadece yanımda duruyor, güvenlik gereği yanımda duruyor. Okul koridorunda dolanmasına falan izin vermiyorum ben dersteyken (Anne 4 [Mother 4], 7 yaşında kız).

25. Çocuk 5'in (Child 5) yemesi bende, uyuması bende. Üstünü giymesi, çıkarması her şey, bütün her şey benim üzerimde. Benim oğlumun yemek problemi var. Şimdi bağırsaklarında problem olduğu için benim oğlum daha bu sene başladı. Hani 6-7 ay oldu mamayı bıraktık. Çok yavaş ilerliyor ama ilerliyor (Anne 5 [Mother 5], 8 yaşında erkek).

26. Şimdi mesela geceleri yatmadan önce altını değiştiriyorum. Normalde başka biri bezlese krem sürmüyor ya da pudra. Onu dökmüyorlar diyelim mesela… Teni bembeyaz bir çocuk. Cildi çok hassas ve idrarını yaptığı anda derisi hemen kızarıyor... Ben ona razı değilim yani her şeyle ilgileniyorum (Anne 5 [Mother 5], 8 yaşında erkek).

27. Hep gözetlemek lazım çünkü çok hareketli. … Tuvalete gidiyor, oraya ıslak mendil koyuyorum artık kendi siliyor. Ama mesela o ıslak mendili orada görmüyor ya, gidiyor kirli sepetinden kıyafet alıyor onunla siliyor. Sürekli arkasında durmak zorundayız, kollamak zorundayız (Anne 6 [Mother 6], 9 yaşında erkek).

28. Hani ne zaman ne yapacağı belli değil, beş dakika sonrasını tahmin edemiyorsun. Sürekli gözümüzün üzerinde olması gerekiyor (Anne 7 [Mother 7] 10 yaşında erkek).

29. Yani bu biraz aslında tartışmalı bir soru. … Yani öz bakımını çoğunlukla kendi halleden bir çocuk. Ama mesela gerekince yardım istiyor ‘’anne yardım et’’ diyor (Anne 8 [Mother 8], 15 yaşında kız).

30. Benim yardımıma ihtiyacı yok, şu anda hayır. Tabii küçükken öyleydi ama şu anda her işini kendi yapabilir. Bana da yardımcıdır her konuda en büyük yardımcımdır. Erkek çocuğu olmasına rağmen çok derli toplu, düzenli bir çocuktur (Anne 10 [Mother 10], 23 yaşında erkek).

31. Şu anda mı? Şu anda her şeyini kendisi yapıyor, aksine sinirlenir yani karışınca (Anne 14 [Mother 14], 26 yaşında kız).

32. Genelde kendi işini kendi görüyor. Tıraşını, banyosunu kendi yapıyor yani öz bakımlarını da kendisi yapıyor. Kendine yumurta da kırar menemen de yapar salata yapıyor çok güzel (Anne 15 [Mother 15], 27 yaşında erkek).

33. Yani şimdi baktığınızda realitede yirmi dört saat gözetiliyor mu? Gözetiliyor. … Şimdi geçen yazdan itibaren yarım saat evde yalnız bırakmaya başladık. Ama kamera sistemimiz var, kamerayla kontrol ediyoruz (Anne 8 [Mother 8], 15 yaşında kız).

34. Çocuk 9'u (Child 9) pek öyle yalnız bıraktığım yok, genelde biri evde olur. Ya aslında kendine de bakar da ben çok şeyim, ben biraz evhamlı bir anneyim. Ya pek tek bırakmam mümkün oldukça. Genelde bir şey olunca baba evde durur ben giderim, ben dururum baba gider (Anne 9 [Mother 9], 22 yaşında kız).

35. Şöyle bir şey yani Down sendromlu bütün çocuklar ne kadar iyi eğitilebilirse eğitilsin, ne kadar iyi düzeye gelirse gelsin birilerine bağımlı yaşarlar… Bu da annedir en başta. Yalnız bırakamazsın. Ne kadar iyi ne kadar iyi dereceye gelsin bu çocuklar bağımlı bize. Bu kadar basit yani (Anne 11 [Mother 11], 24 yaşında kız).

36. Zaten onu evde yalnız bırakamam. Evimizin hemen yanında market var. Komşumun da engelli bir kızı var. "Hadi markete gidelim, çocuklar uyuyor zaten" diyor. Ben de ya çocuğum uyanırsa, ya bir şey olursa nefes alamazsa diyorum. … Çocuk 12 (Child 12) asla evde yalnız kalmaz (Anne 12 [Mother 12], 25 yaşında kız).

37. Sitede yaşıyoruz ve herkes bizi tanıyor. Çocuk 14 (Child 14) benim emniyetli gördüğüm sınırlar içinde free fakat onun haricinde hiçbir zaman bu güvenli bölgenin dışına çıkmasın… Çünkü içinde hiçbir kötü his olmadığı için herkesi öyle zannediyor. Çeşit çeşit insan var, zarar görebilir ve gerçekten böyle bir riske giremem (Anne 14, 26 yaşında kız).

38. Bir annenin başına bir şey geldiğinde normal çocuk da annesiz kalır. Ama diğer çocuklarımda bu düşünceleri hiç yaşamadım ama Çocuk 2 (Child 2) için böyle endişelerim var (Anne 2 [Mother 2]).

39. Tam damarıma bastığınız konular. En büyük kaygılarımız bunlar zaten. Bizim herhalde annelerle beraber hepimizin ana noktası bu. Yani ben şöyle düşünüyorum kimseye yük olmasını istemem. Hep şey diye dua ederiz ya yani hani benden geriye kalmasın, benden önce de gitmesin. Zaten ben böyle hep aynı gün gerçekten göçüp gitmeyi hayal ediyorum. İnşallah öyle kısmet olur hepimize (Anne 4 [Mother 4]).

40. Her zaman düşünüyorum ölürsem ne olacak? O zaten doğduktan sonra bizim aklımıza gelen ilk soru. Bilmiyorum ben bazen ölürsem Çocuk 15'e (Child 15) ne olur diye ağladığım çok oldu (Anne 15 [Mother 15]).

41. Aslında ben bu konuda geleceği konuşmak istemiyorum. Yani çünkü Çocuk 1'in (Child 1) geleceğini düşününce insan daha çok endişeleniyor. O yüzden ben biraz düşünmemeye çalışıyorum herhalde (Anne 1 [Mother 1]).

42. Ben geleceğe dair düşündüğüm zaman zaten çok içinden çıkamıyorum, düşünmemeye çalışıyorum artık. İyi olanı diliyorum bütün çocuklar için (Anne 2 [Mother 2]).

43. Gelecek hakkında konuşamıyorum bile çünkü acı veriyor. … Gelecekle ilgili konuştuğumda eşim hemen konuyu kapatmaya çalışıyor (Anne 16 [Mother 16]).

44. Ya ben aslında şöyle yani çok fazla böyle kötü bir şey düşünme taraftarı bir insan değilim. Hani olaylar daha çok yaklaştıkça böyle bir önlemler almak yani daha mantıklı geliyor. Yani işte on sene sonrasını düşünmek… Tamam, yani tabii ki aklımda, düşünüyorum hani ne olur biter ama on sene sonra ne olup biteceğini bilmiyorum. Onun için şu anda o zaman için öyle bir şey yapmak bana çok doğru gelmiyor… Dediğim gibi belki şu anda ben onun erken olduğunu düşünüyorum (Anne 14 [Mother 14]).

45. Ama şimdi insan ölümü bilmez ki ne zaman gelecek? … Benden sonra ne olacağını önce Allah bilir... Rabbim engelli evladı olan annelere hayırlı bir ömür, uzun bir ömür versin ama sağlıklı ömür versin (Anne 3 [Mother 3]).

46. Gelecek için insan bir şey diyemiyor ki. Ben kendimi de öldürsem benim dediğim değil, Rabbim'in dediği oluyor (Anne 9 [Mother 9]).

47. Ya zaten ben aslında ben ölümü düşünmedim hiç… Yani bu zaten benim düşündüğüm zaman gerçekleşebilecek bir şey değil, herkesin bir kaderi var (Anne 14 [Mother 14]).

48. [Zihinsel engelli ve tek çocuğu olan komşusu ile arasında geçen konuşma) "Ya Anne 12 (Mother 12) dedi bir şey olsa bize, bizim çocuklara ne olacak? Hadi senin çocukların var, seninkiler yapar ama benimkini kim yapacak? Kim bakacak? Tek çocuklu kadın öyle bazı şey yapıyor, dert ediyor. Ben de diyorum ki "aman sen de bunları mı düşünüyorsun şimdi" diyorum, ben de geçiştiriyorum (Anne 12 [Mother 12)].

49. Şu anda ben her yeni işe giren güvenlikçiye otoparka girerken durup, Çocuk 4'ün (Child 4) arkadan camını açıp, onunla iletişim kurdurup durumunu bir şekilde belli ediyorum ya da tek başına yakaladığımda hani söylüyorum çünkü yarın ne olacağını bilmiyorum. … Dolayısıyla biz sadece geleceği aslında bugünden planlamak zorundayız. Ben bugünü de planlamak zorundayım. Nasıl yarını planlamazsınız? Mümkün değil yani (Anne 4 [Mother 4]).

50. Şöyle aslında annelerin kendi imkânları dahilinde çevrelerinde bir destek mekanizmasını inşa etmesi gerekiyor. Bence bu da bir bakım planı. Ailelerin aslında bir bakım planına hayattayken başlamaları gerekiyor. Hani kendileri varken çocuklarına daha iyi nasıl imkânlar tanıyabilirler? Bu da destek mekanizmalarını kullanarak olabilir. Çevredeki destek mekanizmalarının farkına varmak, gerekiyor, bunları yaratmak gerekiyor. Yani bu kolay demiyorum, zor ama bence yapılabilir.

Yani bu bir komşu olabilir, mahalledeki bakkalı olabilir. … Hani baktığınızda biz de kendi destek mekanizmalarımızı yarattık eşimle beraber, hani bunların hiçbiri de bize şeyle gelen, yani bir şekilde başka bir yerden gelen, devlet tarafından verilen destek mekanizmaları değil (Anne 8 [Mother 8]).

51. Örneğin ben şimdi pazara gidiyorum, biraz pazardan kısıyorum… Oradan buradan, kendi babamdan bir iki bir şeyler düştüğü zaman hepsini Çocuk 5 (Child 5) adına atıyorum kenara. Ben maddi olarak ne kadar koyarsam kenara yanıma kar. Hani bazı insanlar var çocuğu için gelen parayla geçinmek zorunda kalıyorlar. O yüzden ben şükrediyorum. Bazen elimizde para kalıyor, eşim hemen bir çeyrek bir şey yapalım Çocuk 5 (Child 5) için diyor bunlar gerçekten çok önemli (Anne 5 [Mother 5]).

52. Mesela bir banka hesabı… Mutlaka olacak Çocuk 11'in (Child 11). Mutlaka olacak. … E miras olayı da zaten onun alacağı bazı şeyler var. Mutlaka olacak ama bu tabii vasisi mesela kardeşi vasisi olur ben ölürsem, kardeşi yönetebilir bu durumu (Anne 11 [Mother 11]).

53. Tabii onun kendine ait belli bir miktar maddi şeyini karşılayacak öyle bir hesap var. O da ablasının kontrolünde olacak bir şey. Bu işte dediğim gibi bir fon gibi düşünün onu ve onun bakımıyla ilgili ne gerektiriyorsa onu karşılayacak bir fon gibi düşünelim (Anne 14 [Mother 14]).

54. Hatta ortanca abi git bir hesap aç ona dedi, para yatıralım falan… Ben gittim onu da beceremedim. Ben de onun adına hesap deyince… Özel çocuk olduğu için onun adına hesap açılmıyormuş, o farklı bir şey demiş. Ben de dedim ki sen biliyordun, sen aç; ben ne bileyim... Daha da gitmedim (Anne 9 [Mother 9]).

55. Şu an mesela benim eşim ticaretle uğraşıyor. Kendi iş yerimiz. Hani biz mesela yatırım amaçlı bir gayrimenkul aldık Çocuk 1'e (Child 1). Şu an eşim tamamen onu ben bunu Çocuk 1 (Child 1) adına aldım diyor. Yani bu onun kendi güvencesi, kendi parası, kendi kira geliri. Yani o tamamen o niyetle alınmış bir şey. O yüzden de tabii ki şu an maddi şeylerde eşim daha çok Çocuk 1'i (Child 1) düşünüyor, hatta o doğduğundan beri daha çok çalışıyor. Şu anda yani onun ileride kimseye ihtiyacı olmadan, hani gerekirse atıyorum hani çalışmadan bile nasıl rahat edebilir, nasıl bir geliri olabilir şu anda tamamen ona odaklı bir şeyler yapmaya çalışıyor (Anne 1 [Mother 1]).

56. Zaten baba diyor ki bir ev var o da kızımın. Tabii ana baba olmayınca ne olur onu hiç bilemiyorum (Anne 9 [Mother 9]).

57. Tabii gelecek adına bir şeyler hazırlayalım hani mülk gibi bir şey bırakalım, ona kim bakarsa ona kalsın diye bir düşüncemiz var (Anne 15 [Mother 15]).

58. Şu anda eşimle ikimizin de olmadığı durum için söyleyeyim. İkimiz de farklı sağlık sigortası sektörlerine dâhil olduğumuz için [anne kamuda, baba özel sektörde çalışıyor] ikimizden maaş, evimiz ve arabamız kalacak. Yani iki maaşla bir Çocuk 4'e (Çocuk 4) bakamayacak durumda olmazlar diye düşünüyoruz (Anne 4 [Mother 4]).

59. Yani şeylerimiz var işte ne bileyim bireysel emeklilik sigortamız, hayat sigortamız falan var. Hani maddi açıdan rahat ettirebilecek bir şeyler yapmaya çalışıyoruz… Şu an bir tek dediğim gibi sigortalar var (Anne 8 [Mother 8]).

60. Bize bir şey olursa Çocuk 10 (Child 10) babasının emekli maaşından yararlanacak. Bilmiyorum başka bir şey yok yani maddi açıdan (Anne 10 [Mother 10]).

61. Kazandığı parayı olduğu gibi zaten ben yatırım yapıyorum bankada. Amacımız zaten bu işe vermekte bizim kendi başını kurtarabilmesi, mümkün olduğu kadar kendi kendini idare edebilmesi (Anne 13 [Mother 13]).

62. Yani emekli olursa emekli aylığı da olacak Çocuk 15'in (Child 15) on yılı geçti, on yıldan beridir çalışıyor yani (Anne 15 [Mother 15]).

63. Ev zaten Çocuk 16 (Child 16) için alındı. TOKİ'den [Türkiye'nin hükümet destekli konut ajansı] aldık bu evi. Engelli kontenjanından yararlandığımız için işlemler Çocuk 16 (Child 16) adına yapıldı… Kurada öncelik işte paraları aynı ödedik… Sonrasında Çocuk 16'nın (Child 16) maaşı ile evin taksitini ödüyorduk. Bir de toplu bir para verilmesi gerekiyordu. Eşim emekli maaşından para çekti, halen ödüyoruz yani (Anne 16 [Mother 16]).

64. Ölüme kadar Rabbim inşallah bize birlikte yaşamayı nasip eder (Anne 3 [Mother 3]).

65. Rabbim el verdiği kadar, sonuna kadar onun yanında olmak istiyorum (Anne 6 [Mother 6]).

66. Benim dışımda bu sorumluluğu bana yakın şekilde yerine getirecek biri sadece baba olabilir. Başka kimseyi göremiyorum (Anne 2 [Mother 2]).

67. Yani zaten sadece ben gittiysem her türlü içim rahat yani. Yani o onda hiçbir endişem yok. Hani baba her türlü ilgilenir bakar eder falan ama tabii ona da zor olur (Anne 8 [Mother 8]).

68. Baba varken baba çocuğunu mağdur etmez. Ben biliyorum. Beceremese de kimseye bırakmaz. Bu Engelsiz Yaşam bizi pandemiden önce bizi Yalova'ya tatile götürdüler. Baktım bir kız çocuk var. Tanımıyorum ama dans ediyor, habire yiyor bir şeyler yapıyor. Dedim ki çocuğun velisi kim? Orada bir adam dedi ki "benim". Baba. Dedim bak siz bu kızı engelleyin, bu kız çok yiyor. Bunlar kilo almayı çok elverişli sonra baş edemezsiniz dedim. Başka bir arkadaşım dedi ki annesi ölmüş, baba ne yapacağını bilmiyor. ... Ay eşim gözümün önüne geldi... Dedim ki bir gün ben olmasam Çocuk 9 (Child 9) ile babası (Anne 9 [Mother 9]).

69. Yani şey tabii erkek olduğu için yani daha çok yük düşüyor babaya. Erkek çocuğu olduğu için hani kız olsaydı belki zordu ama… Hani şu anda babaya güveniyorum (Anne 10 [Mother 10]).

70. Benim dışımda Çocuk 16 (Child 16) ile ilgilenecek… Bir babası ilgilenir işte… Yani ne bileyim öyle bir babasıyla annesi var Başka kimsemiz yok. Ama

babası ilgilenir (Anne 16 [Mother 16]).

71. (Babanın olmadığı bir durumda) maddi olarak ben zorlanırdım çünkü bugüne kadar aldırdığımız bütün derslerin paralarını dizsek buradan köye yol olur hesabı... Özel eğitimi gerçekten özel metotlarla almak zorunda kaldık biz COVID döneminde hiç rehabilitasyon merkezlerine gidemediğimiz için. Eğer tek başıma olsaydım Çocuk 4'e (Child 4) bu hayat kalitesinde bir yaşam sunamazdım. Bakardım yine. Zaten artık büyüdü. Ama ciddi oranda maddi zorluk yaşardım (Anne 4 [Mother 4]).

72. Ya çok zor. Çok şey değişirdi (baba olmasaydı). Yani bir kere o da iki şeye bağlı; maddi imkânların var mı yok mu? Maddi imkânın varsa muhakkak yanıma destekçiler olurdu yani hani bakıcı, öğretmen, vesaire falan. Ama maddi imkânım yok ise sadece bakım odaklı giderdi o zaman. Yani eğitsel şeyler çok az olurdu hayatında. Hani çünkü şu an Çocuk 8'in (Child 8) yaşamına baktığımızda bunlar hepsi maddi imkânlarla olan şeyler (Anne 8 [Mother 8]).

73. Ben ev hanımıyım. Baba hep çalıştı; sabah gitti akşam geldi. Bakmak konusunda bir yardımcı olmadı zaten ama… E başka türlü maddi olarak da tamamen babaydı. Ve sonra bu bakım aylıkları çıkınca babaya da artık pek bir eyvallahım şeyim yok (Anne 9 [Mother 9]).

74. Çok şey değişirdi baba olmasaydı ben de olmazdım. Ya gerçekten ben çocuğu sallarken arkama yaslanıp gece kalkıp bana böyle eliyle su içirmesi, yemek yedirmesi, geçecek bu günlerimiz geçecek demesi Benim eşim dağ gibi arkamda onsuz hayat düşünemiyorum bile (Anne 5 [Mother 5]).

75. Bir de duygusal açıdan da çok zor olurdu. Bir baba desteği yani bir eş desteği kendinize bir hayat arkadaşının desteğiydi… Bu çok ayrı bir şey. Genel olarak ben kendi hayatımda en azından örnek verirsem hani benim için şey tek başına bir anne olmak daha zor geliyor. Ya eşimin yardımı çok önemli (Anne 8 [Mother 8]).

76. Eşim 4-5 yaşına gelip kendini ifade edebilene kadar çocuğu kabullenmedi. O zamanlar zaten o yok gibiydi (Anne 7 [Mother 7]).

77. Önceki yıllarda olsaydık genelde işi gereği yurtiçi yurtdışı gidiyordu o yüzden eskiden olsaydı babasının varlığı yokluğu bir derdim (Anne 13 [Mother 13]).

78. Yani şöyle aslında diğer çocuklarımın da böyle çok hayatlarını etkileyecek bir sorumluluk yüklemek ben hayattayken asla istemem ama söylüyorum hani bize bir şey olması dâhilinde yine bütün sorumluluk ilk önce abilerinindir diye düşünüyorum. Yani bu durumda yine abileri sahip çıkmalı ve yanlarına almalı diye düşünüyorum (Anne 1 [Mother 1]).

79. Kesinlikle yani başkasıyla yaşamasındansa kardeşleriyle yaşamasını isterdim. Hani anne baba onlardan sonra kardeşleri var tabii ki (Anne 7 [Mother 7]).

80. Abilerinden daha çok kime güvenebilirim ki? Yani Çocuk 9 (Child 9) yalnız kalamaz mümkün değil… Bir abinin yanında olabilir, mesela babanın emeklisini o kişi kullanabilir, Çocuk 9'a da (Child 9) o bakar. … Yani diyorum ki Rabb'im

merhametli gelinler nasip etsin bana. Yani abiden çok gelin önemli çünkü bayan o (Anne 9 [Mother 9]).

81. [Konuşmamız] olmadı ama hani abla biliyor ki ona emanet edeceğimizi, onun bakacağını çok iyi biliyor. Yani onun görevi olduğunu da çok iyi biliyor abla. … Ablası da yapar yani ona da güveniyorum. Beraber yaşayabilirler mutlaka yanına alır (Anne 10 [Mother 10]).

82. Abinin ablanın olması falan bana bir güven veriyor. Benim çocuklarımın hepsi ilgilenir onunla. … Oğlum bir gün dedi ki Çocuk 12 (Child 12) benim kardeşim, asla ben onu kimseye bırakmam, onu kız kardeşime, erkek kardeşime bile bırakmam. O beni çok mutlu etti. Ben abileri, ablası varken ben hiç endişelenmem (Anne 12 [Mother 12]).

83. Yani ablaları da sever çok şükür. Bizden sonra sahip çıkarlar diye düşünüyorum inşallah. Ablaları ile kalır diye düşünüyorum ben zaten iki üç günlüğüne diyerekten öyle bırakıyorum onlar da sorumluluk sahibi olsun diye (Anne 13 [Mother 13]).

84. Eğer benim arkamda biri olsaydı, deseydi sana yardımcı olacağım ben o anda başka çocuk düşünürdüm. Erkek isterdim, Down sendromlu çocuğum gibi. Bir tane daha, bir tane daha düşünürdüm (Anne 3 [Mother 3]) (Down sendromlu oğlu ve iki kızı var).

85. … Bazen keşke bir erkek kardeşi daha olsa diye düşünüyorum. En azında ona destek çıkardı (Anne 6 [Mother 6]) (Down sendromlu oğlu ve bir kızı var).

86. Ben çok isterdim bir kızım olsun ama olmadı. Yani nasıl üzülmüşsem ben hemen menopoza girdim. … Bazen anneler korkuyorlar, bir çocukla kalıyorlar. Diyorum ki yanlış yapıyorsunuz. Yapmayın bunu. Yani ikinci çocuğu da doğur, sen olmayınca o çocuk ne olacak? Ama benim olmadı işte... Diyordum ya Rabbim kızım olsun, benden sonra Çocuk 9'a (Child 9) baksın (Anne 9 [Mother 9]) (Down sendromlu kızı ve üç oğlu var).

87. Şimdiki nesle bakıyorum, 25 yaşında ağabey yaşar mı bizimle, yaşamaz mı kestiremiyorum açıkçası. Ama Çocuk 2'den (Child 2) sonra şu oldu keşke bir kızım olsaydı hani Çocuk 2'ye (Child 2) daha böyle şevkatli yaklaşabilecek, ihtiyaçlarını karşılayabilecek... Ya sadece sevmesi için Bir kızım olsaydı hani ben olmadıktan sonra Çocuk 2'ye (Child 2) sahip çıkardı. Ama abiler ile ilgili öyle bir hayale giremiyorum şu anda. Erkekler birazcık daha böyle 18 yaşından sonra bağımsızlığını ilan edip ayrılmak istiyorlar işte bir özgürleşme gibi şey yapıyorlar ama kızlar biraz daha anaç geliyor bana. Ama tabii kızım yok yani ben olmasını isterdim (Anne 2 [Mother 2]) (Down sendromlu oğlu ve iki oğlu daha var).

88. Çocuk 4'ten (Child 4) büyük çocuğum olsaydı bir alternatifim olmazdı yani. Mutlaka iki çocuklu kadın olacaktım ve ikincisi Downlu olduğu için planımı ona göre düzenleyecektim. … Ama ikinci çocuk olduğunda ya da varsa ve bunu gerçekten kardeşe sahip çıksın diye doğuran o kadar çok tanıdığım insan var ki. Bu beni üzüyor. Ben böyle bir yükle gerçekten doğmak istemezdim. Şimdi düşünüyorum benim çocuğum neden kardeşine bakmakla yükümlü olsun? Ya da

neden bana bakmakla yükümlü olsun? O yüzden ben mutlaka bir plan yapardım. İkinci çocuğum olsun veya olmasın... Onun kardeşine mütemadiyen bakması benim isteyeceğim bir şey değildi (Anne 4 [Mother 4]).

89. Zaten genelde mesela ilk çocuğu Down sendromlu olanlar bir tane daha çocuk yapıyorlar. Kendime soruyorum öyle bir şey olsaydı ikinci çocuğu ister miydim? Benim şimdi engelli çocuğum oldu fakat bir anne olarak bir problemi olmayan bir çocuğum da olsun isterdim. Birçok insan da böyle düşünebilir diye düşünüyorum yani… Çünkü o farklı bir şey. Ama ister istemez engelli olmayan çocuğa yüklediğin bir sorumluluk da oluyor (Anne 14 [Mother 14]).

90. İyi insanla karşılaştırsın rabbim ablasını da. Önemli olan sadece ablası değil, onun da karşısına kimi çıkartacak. Çok iyi görünür ama evlendikten sonra kurt olur bilemiyorum ki… Onun için ben oğlumu kimseye emanet etmektense yerleştirsin her tarafa kamerasını koysun dairesine. Oğlum kendini idare ettirebildiği kadar bakıcısı da yanında olur. … Ablasına hiç zahmet vermeden oğluma evde bir bakıcı tutacak birikimi yaparım (Anne 5 [Mother 5]).

91. Bizim asıl isteğimiz kendi evinde yaşaması, bakılması. … Şöyle bir planımız var yani hani bir tane evi olsun ve orada hani biriyle yaşasın, bakım veren biriyle hani plan derseniz öyle bir plan var. Evde, işte kamera sistemi olacak. Kardeşi de hem kamera sisteminden hem ziyaret ederek onu şey yapacak kontrol edecek (Anne 8 [Mother 8]).

92. Konaklamayla ilgili yani Çocuk 14'ün (Child 14) ablasıyla onu konuşmuştuk. Onun dediğine göre hani benim oturduğum yere yakın, aynı bina da olabilir diyor. Yani yakında bir yerde, ulaşabileceği bir yerde oturması. Aynı evde değil ama. Zaten hani ben de ona çok sıcak bakmam yani (Anne 14 [Mother 14]).

93. Abi var bakar ama evleneceği hanım bakar mı bakmaz mı onu bilemiyoruz… Ama Çocuk 15 (Child 15) kendini idare edebilir. Yani anca ona göz kulak olacak, hayatında ne oluyor ne olmuyor diye bakan biri olursa Çocuk 15 (Child 15) yaşantısını devam ettirebilir (Anne 15 [Mother 15]).

94. Evde isterim. Kimsenin olmadığı mesela anne baba kimse yardım etmiyorsa tabii ki başkasının evin işini yapmasını, sağlığıyla ilgilenmesini, yanında kalmasını isterdim (Anne 16 [Mother 16]).
[Yani bu kişiyi hani devlet mi görevlendirsin istersin isterdiniz yoksa hani yine kendi yakınınız, tanıdığınız birisi mi olsun isterdiniz? (Araştırmacı)]
Ha devlet atasın isterdim. Kendi yakınım yani yapacak mı bakalım düzgün bir şekilde? Devlet atadığı zaman hiç olmazsa düzenli yapar, kontrol edilir (Anne 16 [Mother 16]).

95. Aklımda olan mesela bir diğer alternatif de şu; atıyorum hiç kimse bakmasa o para yine Çocuk 4'e (Child 4) bir bakıcı tutmaya yetecek bir para olduğu için böyle çok ton ton teyzeler olur ya böyle gönülden bakar. Ya o tarz biri de bakacak olsa mesela bu da beni çok mutlu eder... Gerçekten böyle bir alternatif de mesela devlet tarafından sunulsa mutlu olurum. Birisi görevlendirilse maaşı ödense, sigortası ödense ve onun tek işi her sabah Çocuk 4'ün (Child 4) yanına gelip, günü birlikte

geçirip, akşam evine gitmek olsa. Böyle bir alternatif de olsa isterdim (Anne 4 [Mother 4]).

96. Kendi ailemiz çok kalabalık. Eşimin ailesi yani böyle amcaları çok, halaları çok. Bana bir şey olduğu zaman bu sorumluluğu kim üstlenir desem yine eşimin tarafından insanlar üstlenir gibi geliyor (Anne 1 [Mother 1]).

97. Biz avukatlarımızla bu işi konuştuk aslında. Onlardan şöyle bir geri dönüş aldık. Ben atıyorum yazılı bir belge bırakıp, benim çocuğum ben öldükten sonra şu şahsa teslim edilecektir diye bir şey söyleyemiyormuşuz. Öncelikli olarak diyor birinci derece akrabalara devlet sorar tek tek. Biliyorsunuz ki bu mahkeme süreciyle oluyor yine. Abimden başlar. Abim almak istiyor mu? Ekonomik durumu ona bakmaya yetecek mi? Ya da benim paramı yönetmeye akıl yerinde mi? Hepsini tek tek değerlendirir ve en yakın akrabalık ilişkisine verir diyor. Şimdi atıyorum ben abimle küs olsam abime verilmesin diye bir şey söyleyemiyorum resmîleştiremiyormuşuz henüz. Şu anda hiçbir şey yapamadık. Önceliğim oydu benim. … Özellikle yengemin adının geçmesini istemiştim ben çünkü abimden ayrılsa Çocuk 4'ten (Child 4) ayrılmaz (Anne 4 [Mother 4]).

98. Bir de dayısı ile yengesi var. Onlara da söyledim. Yengesi ile dayısı çok merhametli. Onlara söylüyorum başka da kimse yok (Anne 5 [Mother 5]). [Yani siz böyle bir konuşma yaptınız mı dayı ile ya da yenge ile? (Araştırmacı)] Tabii tabii benden sonra oğlum size emanet dedim (Anne 5 [Mother 5]).
[Nasıl bir cevap aldınız? (Araştırmacı)] Başının üstüne diye (Anne 5 [Mother 5]).

99. Ben çocuğumu sadece özel gereksinimli bireylere yönelik yerlere yollar mıydım bilemiyorum… Yine daha normal insanlarla birlikte olmasını isterdim gibi geliyor (Anne 1 [Mother 1]).

100. Kurum bakımı asla ve asla istemiyoruz yani onu söyleyebilirim. Ne var bilmiyorum ama ne yok olduğunu söyleyebilirim, kurum bakımı yok mesela (Anne 8 [Mother 8]).

101. Kurumsal bakımı düşünmüyorum bile. Yani kendileri bakar, yani evlerinde bakarlar. Valla ona hiç düşünmedim ben şimdiye kadar (Anne 10 [Mother 10]).

102. Ayy çok hazırlıksız yakalandım… Kurumsal bakım… Yani kimsesiz kalması gerekiyor böyle bir şey için Allah korusun. Yani hiç aklıma getirmek istemiyorum (Anne 11 [Mother 11]).

103. Yani kurum bakımı şöyle, kurum bakımı niye hayır? Yani kurum bakımı hakikaten çok çaresiz kalındığı noktada bir çözümdür çünkü kurum bakımı çok korkunç. Yani kim ne derse desin. Şimdi devlete sorsanız çok iyi kurum bakımları ama değil. Artı kurum bakımı hani yani hiçbir sosyal aktivitenin olmadığı, kişilerin izole edildiği falan yerler özellikle engelliler için. Sadece Down sendromlu için de fiziksel engelliler için de izole bir hayat yaşamak durumunda kalıyorlar (Anne 8 [Mother 8]).

104. İlk endüstri meslek lisesine yazıldığında özel sınıftaydı. Bir çocuk gelirdi kurumsal bakımdan… Yani çok sevgiye muhtaç, çok kötü durumdaydı. O yüzden

ben hiçbir kuruma güvenmiyorum, özel de aynı devlet de aynı. Allah düşürmesin kimseyi (Anne 10 [Mother 10]).

105. Devlet yapar ama çalışan insanlar nasıl davranacak onu da bilmiyorum. Bunun yapılabilmesi için eğitimin şart olması lazım. … Hani okullar, evler, hani onların rahat yaşayabileceği evler yapılsın ama… … Orada çalışan insanların onlara davranışları için önemli benim için (Anne 10 [Mother 10]).

106. O evdeki sıcaklık, o sarılma yok… Biliyorsun bizimkilerin sarılma sevdasını… Bir de güven var. Güvenmiyorum (Anne 11 [Mother 11]).

107. Ya işte planladığım bakım verenler de olmazsa mecburen devlet kontrolünde bir yere, güvenli bir yere yerleştirilmesini isterdim. Çünkü her şeyimiz var, ona bakabilecek paramız var ama çocuk vasisi olmadan bunu harcayamayacak bir durumda olan çocuk. Tabii ki de evde kalması her zaman önceliğim olur, alıştığı ortamda kalması. Ama kurumsal bakıma da mecbur kalındığı şartlarda önyargılı değilim. İletişimin kopmayacağı, kendi içine kapanmayacağı bir sosyal ortam yaratılabildiyse gerçekten orada mutlu olur Çocuk 4 (Child 4). Fiziksel olarak zarar görmüyorsa, karnı doyuyorsa, hijyen şartları sağlanıyorsa Çocuk 4 (Child 4) orada mutlu olur (Anne 4 [Mother 4]).

108. Eğer abi anne baba kardeşler sağ ise evde olmasını tercih ederim ama bu tabii ki kimse yoksa kurumlar daha iyi olur. Onların var olması insana destek veriyor yani hiç kimsenin olmadığı bir durumda oraya gideceğini bilmek insana bir rahatlık veriyor (Anne 7 [Mother 7]).

109. En azından yine öyle kurumlar güzel, en azından bir seçenek olarak olması güzel yani. Hiç olmamasındansa olması iyi bir şey (Anne 9 [Mother 9]).

110. Tabii ki fırsat olursa evde yaşamasını tercih ederim ama diyelim ki hiç öyle bir fırsat yoksa tabii ki o da mecburiyetten. Önemli bir şey yani olması gerekiyor [kurumsal bakım seçeneğinin]... Ama bunun belli bir standardın da üstünde olması lazım. Her birinin böyle ayrı odası olması lazım. Keşke öyle bir şey mümkün olabilse… Devlet tarafından finanse edilse de hani belli bir standardın da üstünde olması lazım (Anne 14 [Mother 14]).

111. Ama bu arada şunu da söylemem gerek mesela biliyorsunuz siz, kırk yaşından sonra Alzheimer gelişme riski çok fazla. Hani kurum bakımı asla dedim ama bu tip bir durumda ben yok isem kurum bakımı öneririm kardeşine. Yani çünkü o çok zor. Hani Alzheimer benim etrafımda var, bir yerden sonra evde bakım çok mümkün halde olmuyor yani. Hani sağlık açısından bir bakıma da ihtiyacı var ise devreye almak bir seçenek olabilir. Yani o seçimi rahatlıkla yapabileceği güvenli ortamı engelli olmayan kızıma sağlarım duygusal olarak. Hatta hani olabilir, durumları olmayabilir bizden sonra… Kardeşi bir bakım evinde kalacak olabilir, takip ettiği sürece kalabilir yani. Hayat bu. Hani o açılardan da ona öyle bir yük bindirmek istemiyorum. Herkes de bir şekilde kendi hayatında yaşamak durumunda. Bunu söylemek de çok kolay değil. Tabii Çocuk 8 (Child 8) için üzülüyorum elbette yani ama ikisi de evlat. Yani yani yapacak bir şey yok (Anne 8 [Mother 8]).

112. Çocuğumun bir maaşı olmasının isterim ufak tefek yine de onu kalkındırabilecek bir maaşın (Anne 1 [Mother 1]).

113. Öncelikle engelli maaşı mesela olmasını hakikaten istiyorum (Anne 11 [Mother 11]).

114. Birincisi Down sendromlu gibi zihinsel özel gereksinimli kişilerin çalıştıkları zaman dahi devlet tarafından destek alıyor olması gerekiyor. Özellikle yaş ilerledikçe artan bir sağlık ihtiyacı olabilir, farklı ihtiyaçları olabiliyor ve bu masrafların altından çalışarak kalkması mümkün değil (Anne 8 [Mother 8]).

115. Eğer bağımsızlığından bahsediyorsak da yani çalışarak alacağı maaş ile bir evde yaşaması hem bakıcısı vesairesi mümkün değil asgari ücretle. Çünkü bu kişiler asgari ücret ya da çok az üstüne alabilirler. Yani o şirket politikasının alt seviyedeki şeyi neyse çünkü pozisyon olarak o pozisyonlarda çalışabiliyorlar. Hani müdür, genel müdür gibi daha hani yönetsel pozisyonlarda çalışamıyorlar. Farklı bir durum olur asgari ücretten daha fazla maaş alma durumu olursa çalışmaya başladıklarında aldıkları maaşa göre yardımların kademeli azalması söz konusu olabilir ama asgari ücret alıyorsa hiç kesilmeyecek (Anne 8 [Mother 8]).

116. Sosyal yardımların aile gelirine göre değil bireyin kendi gelirine göre belirlenmesi gerekiyor ve bireyin kendisine veriliyor olması gerekiyor. Bakım yardımını da bireyin kendisine verilmesi gerekiyor ve birey kendi seçtiği bakıcıya bunu ödüyor olması gerekiyor. Ne olursa olsun. Eğer bunu yapamayacak durumdaysa yine onun hesabına yatar artık vasi ya da vekil, velayet sistemi üzerinden o, onun şeyi yapılır artık ama böyle olması gerekiyor (Anne 8 [Mother 8]).

117. Zihinsel engelli mesela erkek çocuklarının baba emekli maaşını hani alamaması gibi şeyler var ya bunların zaten olmaması gerekiyor. Dahası vasi tayin edilmemişse bile bunları alabiliyor olması gerekiyor. Para her sorunu çözer demiyorum ama parasız hiçbir sorunun çözülmeyeceğini biliyorum (Anne 8 [Mother 8]).

118. Sadece anneden ya da sadece babadan alınabiliyor öldükten sonra maaşlar çocuğa öyle gidiyor. Mesela bu çocukların ikisinden de alabilme hakkı olmalı. … Çalışsa da çalışmasa da alacak ama çalıştığında kazandığı maaş oranına göre alacağı pay azalabilir. Bu almama gibi bir durum söz konusu olmaması gerekiyor (Anne 8 [Mother 8]).

119. Bizler çalışırken bir fon oluşturulabilir. Biz zaten bordrolu çalışanlar gelirlerinin yüzde kırkını, kırk beşini zaten vergi olarak veriyoruz bordrodan. Devlet kendi kısmından bir kısmını almayacak; diyecek ki yüzde yirmi oranında ben bunu engelli çocuğun için ayırdığım fona aktaracağım. Aynı bir SGK mantığında. Bu ayrı bir fon olacak. Çocuk bizim ölümümüzden sonra nasıl benden bir maaş alacak bir de ek olarak buradan gelen maaşı alacak. Ama bu ikisi birbirine kesmeyecek yani bunlar birbirine üstüne gelecek şeyler (Anne 8 [Mother 8]).

120. Yani şeylerimiz var işte ne bileyim bireysel emeklilik sigortamız, hayat sigortamız falan var. Hani maddi açıdan rahat ettirebilecek bir şeyler yapmaya çalışıyoruz… Şu an bir tek dediğim gibi sigortalar var (Anne 8 [Mother 8]).

121. Bize bir şey olursa babanın emekli aylığı ona kalır. Ondan sonra ne bileyim herhalde başka da bir şey yok yani hani maddi açıdan (Anne 10 [Mother 10]).

122. Yani ben şimdi şu anda para biriktiremiyorum diyelim ki çocuğum için, hiç olmazsa o vesileyle para biriktirmiş olacağım. Burada da devlet kendi alacağı verginin gelir vergisinin yüzde yirmisini atacak. Belki de diyecek de yüzde beş de sen katkı ver. Hani yüzde beşi kadar da aile katkı verecek. Diyelim ki her ay orada zaten bir 8000 lira atıyorum maaş alıyorsanız zaten 8000 lira da devlet alıyor kurumdan çalıştığımızda yani. Onun diyecek ki ben almıyorum dördünü, senin için çocuğunun şeyine yatırıyorum diyecek. Yani böyle bir sistemin olması gerekiyor. Ama hiçbir şekilde gerçekten engelli kişiye, özellikle zihinsel engelli kişilerin gelirinin kendisine gelen yardımların tamamen kesilmesini engellemesi gerekiyor çünkü o gelir zaten geçinebileceği bir gelir olmuyor yani ihtiyaçları karşılayacağı gelir olmuyor (Anne 8 [Mother 8]).

123. Ya ilk, ilk etap hep böyle şey diyor ya en az sınırlandırılmış ortam diye bir şey var biliyorsunuz eğitimde, bence bakımda da öyle olması gerekiyor. En az sınırlandırılmış ortamdan yola çıkarak başlanıp ilerlenmesi gerek ve belli bunların bir deneme sürelerinin de olması gerekiyor. Yani kişinin önce evinde uygun destekte bakılması. Başarısız olunuyorsa neden olunduğunun tespit edilmesi, onun tekrar desteklenerek o çözümlerin üretilmesi… Bu şekilde olması gerekiyor. Yani tek başına evinde ya da biriyle beraber işte devlet gerekli desteği sağlayacak. Bütün desteği sağladı, her şeyi yaptı, artık olmuyor. Kişinin mesela makineye bağlı ya da böyle sürekli bir tıbbi şeye ihtiyacı var diyelim ki, e o zaman artık evde olmuyor, o zaman kurum bakımı düşünülmeli. Ya da çok ciddi, sürekli bir şey takibinde, sağlık takibinde olması gerekiyorsa ya da ilaç kullanıyorsa, bilmiyorum artık onun şeyi nedir bilmiyorum ama şu olmamalı ‘’ya biz bunu yaptık, işte buna bakıcı sağlayamıyoruz; evde çok şey hadi bunu kuruma alalım’’ öyle bir şey olmamalı (Anne 8 [Mother 8]).

124. Kesinlikle kendi evlerinde yaşam desteğinin veriliyor olması gerekiyor. Yani kira yardımı, elektrik, su gibi şeylerin muafiyeti gibi bu tip desteklerin olması gerek bu kişilere. Doğal gazdan muaf olacak, elektrikten, sudan muaf olacak. O zaman tamam, sadece maaşını alsın onunla geçinir ama onun dışında eğer bunları yapmıyorsa muhakkak ek bir gelir sağlaması gerek. Çocuğun başka türlü hayat kalitesini sağlamak çok mümkün değil yani. Bir de o zaman kurum bakımına zaten gerek kalmaz. O zaman evde bakım yapılabilir (Anne 8 [Mother 8]).

125. Temizliği hiç sevmiyor Çocuk 13 (Child 13). Ev temizliği, evde yemek belediyeler gönderiyor ama belli bir kriterler var orda da. Evin olmayacak maaşın olmayacak ama aslında bu çok saçma bir şey. Bu ihtiyaçlar bedensel diye düşünmüyorlar, fiziksel diye düşünmüyorlar maddi yönden bakıyorlar (Anne 13 [Mother 13]).

126. Benden sonra birinin vallahi işte evin işini yapmasını, sağlığıyla ilgilenmesini isterdim. Vallahi yiyecek konusunda da şimdi Çocuk 16 (Child 16) birazcık kilo alıyor ya. Yemekleri ona göre hazırlıyorum, ekmeğini falan… Herkes her şeyini yapamaz, buğday unuyla yapıyorum ekmeğini (Anne 16 [Mother 16]).

127. Az önce bahsettiğiniz gibi evde tabii ki de tercih ederim. Kendi düzenli ortamında olsun isterim. Ama sosyalleşme olayı da tabii insanın kafasını kurcalıyor. Yani evde tek başına mı kalacak bu çocuk? (Anne 4 [Mother 4]).

128. Bu aslında bakımın da ötesinde bir şey çünkü bakım dediğiniz zaman sadece bakım sağlamaya odaklanılıyor. Sadece işte kişi hijyeni ve temizliği işte fiziksel olarak iyi mi? Yemeğini yiyor mu, tuvaletine gidiyor mu? Bakım denince bunlar. … Yani birtakım ruhsal ihtiyaçlar da var. Nedir? Arkadaşlık, sosyallik, işte bir şeyleri öğrenme, bir uğraş… Bunlar mesela kurum bakımlarının içerisinde olmayan şeyler. Hani yazıda olabilir, evet ama uygulamada olmayan bir şeyler. Kültürel, sosyal etkinlikler, spor vesaire neyse işte bir alışveriş merkezine gitmek, dışarıda arkadaşlarınla bir çay içmek, kahve içmek gibi gibi bunların bunların da olması gerek (Anne 11 [Mother 11]).

129. Yani şu an aklıma gelen bir şey var saçma gelir mi bilmiyorum ama nasıl evlat edinmek isteyen koruyucu aileler oluyor ya aynı şeyin engelli bireyler içinde olmasını isterdim yani kaç yaşında olursa olsun bir kurumda olsa bile koruyucu ailesi olmasını isterdim gibi geliyor. Böylece yalnız kalmaz ve hiç olmazsa sosyalleşir (Anne 1 [Mother 1]).

130. Kurum bakımı dediğinizde büyük kurumlar olmamalı, en büyüğü Umut Evleri gibi olmalı. Ama şöyle yani onların da küçük kurum bakımlarına dönme riskleri var her zaman. Hangi ülkedeydi hatırlamıyorum… Mesela onlar bütün kurumlarını kapamışlar, kurum yok artık. Kurum bakımı yok. Onun yerine Umut Evi gibi küçük evlere dönmüş ama diyor ki şimdi kurumlarda yaşadığımız problemleri oralarda da yaşıyoruz. Yani o küçük yerlerde de yaşamaya başladık. Nedir o? Hani izolasyon durumu, bakım kalitesi, şeffaflık gibi. Hani o yüzden kişisel asistanlık sistemi diyorlar, kişinin asistanını kendi seçmesi diyorlar falan filan. Yani bütün bu sistemler tabii bir miktar hepsi istismara açık olabilir. Kişisel asistan da aynı şekilde istismara açık olabilir. O yüzden bunların iyi denetlenmesi sanırım esas. Hani bir işte serbest denetçiler ya da bağımsız denetçiler neyse… Bağımsız denetçiler tarafından denetlenmesi bir şey olabilir (Anne 8 [Mother 8]).

131. Ama şöyle bir planımız var yani hani bir tane evi olsun ve orada hani biriyle yaşasın, bakım veren biriyle hani plan derseniz öyle bir plan var. Kardeşi de ara ara şey yapsın, evde işte kamera sistemi olacak kardeşi de hem kamera sisteminden hem ziyaret ederek onu şey yapacak kontrol edecek (Anne 8 [Mother 8]).

132. Oğlumun kendi kendine idare edebilmesi için yanında bir bakıcı bulunacak. Masrafları bana ait olmak üzere veya kamu tarafından finanse edilen bir bakıcı tutardım. Bir yabancıyı işe almazdım. Rabbim kimseyi sebepsiz yaratmadı. Kız kardeşinin ailesi olacak. Kız kardeşine sorun çıkarmadan oğluma evde bakıcı tutmak için para biriktireceğim (Anne 5 [Mother 5]).

133. Yani anca ona göz kulak olacak, hayatında ne oluyor ne olmuyor diye bakan biri olursa Çocuk 15 (Child 15) yaşantısını devam ettirebilir (Anne 15 [Mother 15]).

134. Devlet versin parasını ama ben kendim tutayım yani ben olmasam bile güvendiğim insan evime girsin çıksın isterim. Devlet onu nasıl olduğunu bile bilemez ki ben şimdi çevremde atıyorum mesela teyzemin kızı ihtiyaç sahibi.

Teyzemin kızı yani biliyorum iyi bir insan olduğunu, ona devlet versin parasını o bakar, devlet o şekilde karşılasın (Anne 5 [Mother 5]).

135. Çocuğumun bir maaşı olmasının isterim ufak tefek yine onu kalkındırabilecek bir maaş. Tabii ki ona da bakan kişinin de bir devlet desteğinin olmasını isterim. Ayrı ayrı yani şu yaşam şartlarında gördüğünüz üzere maalesef yani bi bireyin geçinmesi çok zor (Anne 1 [Mother 1]).

136. Hem sorumluluk alıp hem de kendinden veremez hiç kimse, akrabası olsun olmasın hiç önemli değil bir ödeme alması gerekir (Anne 4 [Mother 4]).

137. Valla aylığı kesilmesin isterim nereye giderse gitsin daha sonra gittiği ev faydalansın. Ayrıca, ben şu an suyumu yarı yarıya kullanıyorum diğerlerinde de öyle olsun yani. Bana ne yapılıyorsa gittiği zamanda o şekilde olsun isterim (Anne 5 [Mother 5]).

138. Bir anne baba neyden yararlanıyorsa bakım veren hani illa ebeveyn olması gerekmiyor aynı şeylerden yararlanıyor olması gerekiyor. Bu erken emeklilik olabilir, bakım parası nakdi destekleri olabilir. Ondan sonra işte o şey eğitimler olabilir hem ailenin alacağı hem kişinin alacağı eğitimler olabilir. Yani aslında normal şartlar içinde ebeveynler için düşünülen her türlü desteğin bakım veren olarak genişletilmesi gerek (Anne 8 [Mother 8]).

139. Bir de şeyi anlamıyorlar yani mesela diyorlar ki normal olsaydı da bakacaktın... İyi de farklı alternatifler var. Onu daha sıradan büyütürken daha sıradan masraflar yapacaktım. Ben şimdi onun yerine belki de üç kat masraf yapıyorum. Gözlüğü atıyorum 200 lira verecekken biz 1000 lira vermek zorunda kalıyoruz. O aradaki farklı oranı da anlamaları çok zor (Anne 4 [Mother 4]).

140. Zaten öngöremediğimiz maliyetler de söz konusu olur. Atıyorum gözlük, yani gözlük camı inceltmek bile bir maliyet. Ya şey Çocuk 8'in (Child 8) gözlüğü özel bir gözlük cam, 3000-5000 lira camı. Yani hepsi bunların maliyet yani. Mesela şey var skolyozu var, herhangi bir hastaneye götüremiyorum ben onu. Yani skolyozla ilgili uzmana götürüyorum, devlette bunlar yok ya da devlette o hizmet için çok uzun bekliyorsun. Diş mesela dört sene, beş sene ya. Yani olabilecek şeyler değil. Dolayısıyla en azından engelli kişiler için ya da ben şu an Down sendromu, zihinsel engeller için konuşuyorum, bu hizmetlerin hem özelde hem devlette sınırsız olarak alınabilmesi gibi ek şeylerin olması gerekiyor. Artık orada nakit vermek ya da hizmet vermek orada devlet karar verebilir. Ben aldığım hizmetin niteliğine bakarım. Bunu ister devletin verdiği parayla alıyor olayım, ister devlet parasını özel eğitim rehabilitasyon merkezleri gibi yerleri ödüyor olsun ben gideyim istediğim yerden hizmete alıyor olayım. O fark etmez. Hatta o ikinci seçenek belki çok daha iyi çünkü zihinsel engellerin para kullanması açısından da daha iyi olabilir ama ellerine de kendi kazançları geçiyor ve evini idame ettirebiliyor işte ne bileyim bakıcısının seçebiliyor falan olması gerekiyor (Anne 8 [Mother 8]).

141. Şu bakanlığın bir düzen getirmesi lazım ya da Sağlık Bakanlığı'nın. … Yani hem çok daha uzun beklenen hastaneler oluyor. Gerçekten çok isterdim Türkiye'de Down sendromlarla ilgili ayrı bir bölüm, ayrı bir hastane… Gerçekten böyle bir hayalim var. Mesela hastanenin bir bölümü, üç dört katı sadece Down sendromlular

için olabilir… Endokrin bölümü, genetik bölümü, ortopedi ölümü, fizyoterapi bölümü... Bunların olduğu Down sendromu hastanesi olması gereken bir şey (Anne 11 [Mother 11]).

142. Çocuk 11'e (Child 11) için ilk aldığımız rapor %40'tı. Sonra işte benim bazı şeylerden yararlanmak için istememle %51'e çıkardılar. Sonra fark ettim ki hani buna hiç gerek yok. Hiçbir şey doğru değil aslında bu sistemde. Ne eğitimde, ne sağlıkta, ne raporlarda, sistemde hiçbir şey doğru değil. Bir de ben Down sendromlu çocuklara bir oran koymalarına, raporu yeniletmelerine çok kızıyorum. Down sendromu değişmeyecek bir genetik farklılık. Hani mesela ben bazı şeylerden faydalanmak için %90 raporunun peşinde koşmaman lazım. Evet, benim çocuğum %90 değil. Ama eğitim aldı diye, öyle böyle konuşuyor diye de buna bir oran koymamaları lazım. Neden ben mevcut haklarımdan yoksun olayım çocuğum kötü ama çok da kötü değil diye… Mesela yalnız başına otobüsle ya da bir yere seyahat gidemeyeceğine göre bu ailenin arabaya ihtiyacı var (Anne 11 [Mother 11]).

143. Yüzde 70 olarak yaptırdık, aslında %50'lerde. Çocuk 15 (Child 15) çalıştığı için evde bakım falan almıyor. Engelli kartını kullanıyoruz sadece toplu taşımayı ücretsiz kullanıyoruz. Önceden %50 rapor gözüküyordu ve bu haktan yararlanamıyorduk. Yani sadece Çocuk 15 (Child 15) ücretsiz biniyordu, ben para ile biniyordum ama zaten bensiz binemezdi ki… Sonrasında engellilik oranı %70 e çıktığında artık yanında binen kişi de ücretsiz kullanabiliyor. TOKİ'ye de yazıldık ama çıkmadı, araba da alamıyoruz %95 engel istiyorlar (Anne 15 [Mother 15]).

144. Bir niyet mektubum var. Bunu noter aracılığıyla yapabilir ve evinizin bir köşesine bırakabilirsiniz. İmzalandığı sürece sorun yok. Bunu kendi ailem de biliyor, avukat da biliyor. Bu arada eşim de biliyor ki bu bizim ortak kararımız. Yani mantıklı düşündüğünüzde ve bu çocuğa kimin bakacağını sorduğunuz zaman, bakıcı olarak kendi akrabanız ile kocanın akrabası arasındaki ayrım ortadan kalkıyor. Ona gerçekten en sağlıklı şekilde bakabilecek kişiyi seçtik. Potansiyel bakıcısı da bu niyet mektubunu biliyor. Zaten sorun olmadığını söylediği için yazabildik. Yengem. Ona sordum, o da kabul etti. "Elbette ilgilenirim" dediği için bunu yazılı olarak bırakabildik (Anne 4 [Mother 4]).

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