



ESPN Thematic Report on Challenges in long-term care

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Summary

Turkey has an ageing population and according, to the latest available data, in 2002 12.29% of the population were disabled and of those almost 80% were chronically disabled. The rate was 36.96% among those aged 60-65 and 43.99% among those older over 70. The official documents and legislation acknowledge that a rational, systematic and sustainable system should be established and assign responsibility for the provision of services to both elderly and disabled people of all ages to the Ministry of Family and Social Policies (MoFSP).

Institutional capacity has been growing rapidly over the last decade. The MoFSP reports that there is no waiting list for care and rehabilitation centres for the disabled. It should be noted that this is largely because capacity is restricted to disabled individuals with no family member to provide care. Those living with family members and with no means of paying for private facilities are directed to the home care programme; under this scheme, about half a million poor households are provided with payments to care for disabled family members. As for the nursing homes, public capacity is inadequate to meet the need; private providers are few, are concentrated in metropolitan areas and are expensive.

Regarding the work-life balance, benefits and social assistance for people caring for relatives are rather limited; there is no leave available to employees for the care of dependants (with the exception of government employees and the parents of children with disabilities).

Carers are often women and they usually work informally. Training programmes for carers are largely lacking. The payment to those providing care to family members under the home care programme is considered a social benefit and no social security contributions are paid on behalf of the carers. Also lacking proper training, these individuals are likely to have difficulty in participating in the labour force in the future.

Official documents emphasise the importance of multidisciplinary and interdisciplinary services and a comprehensive approach, including preventive treatment and rehabilitation services. Yet, while awareness has increased over time, no systematic plan has been implemented.

To improve access to care services, the number and quality of rest homes, as well as of care and rehabilitation centres, should be increased. Coordination should be established among different institutions that provide support to the elderly. While care provision by relatives at home may offer a solution to the increasing need for services, it is clear that such a system requires a number of support mechanisms (such as an efficient training programme) to operate efficiently. Introducing paid leave and institutional respite support would ease the labour force participation of family members.

Finally, data to assess long-term care needs are largely lacking, with the latest survey dating from 2002. Also lacking is an evaluation of the home care system, which currently covers around half a million households.

1 Description of the main features of the country's long-term care system(s)

In Turkey, 8.5% of the population in 2017 was aged 65 years or older. The number of individuals over 65 increased by 17.01% in the period 2012-2016. The old-age dependency (which is the ratio of older dependents to the working-age population) also increased—from 11.2% in 2012 to 12.3% in 2016. According to the Turkey Disability Survey, conducted in 2002 (Presidency of Administration on Disabled People and Turkish Statistical Institute, 2002), of the entire population, 12.29% is disabled, with the proportion of disability due to chronic disease standing at 9.7%; the disability rate is 36.96% among those aged 60-65 and 43.99% among those over 70. The Turkish Family Structure Survey of Turkstat and MoFSP found that 6% of all households have an elderly

member who needs care. There is a need for updated nationwide prevalence data on disability and related issues.

Law No. 5378, entitled 'Law on the Disabled', was passed in 2005 and seeks 'to prevent disability, to enable people with disabilities to participate in society by taking measures which will provide solutions to their problems regarding health, education, rehabilitation, employment, care and social security, to remove the obstacles these people face, and to make the necessary arrangements for the coordination of these services'. The Law stated the importance of care services, and described how and by whom these services would be provided. In 2011, Law No. 633 gave the Ministry of Family and Social Policies (MoFSP) responsibility for providing services to both elderly and disabled people of all ages. A General Directorate of Disabled and Elderly Services was established within this Ministry. The Ministry of Health and the Ministry of Labour and Social Security are also indirectly involved in providing services for the elderly – the former providing healthcare services and the latter retirement benefits. As is the case with various social services, some municipalities are active in providing care services to their communities; but since 2014, care services operated by municipalities and other public institutions have come under the supervision of the MoFSP (under Law No. 6518).

There are institutional mechanisms for the elderly and people with disabilities in terms of long-term care (LTC), mostly in the form of rest homes. The number of those operated by the MoFSP has increased, but the coverage of long-term care services by the government is rather limited. As of January 2018, they had capacity for 14,793 people, while the number of beneficiaries in the 144 institutions was 13,692 (82% higher than the capacity of 8,126 in 2009) (MoFSP, 2018).

As the elderly population increases each year, so the need for hospital care and intensive care unit (ICU) beds is also expected to rise. There were 4.1 ICU beds in hospitals per 10,000 population in 2016, after a rising trend which started after 2003.

For the disabled, public care and rehabilitation centres feature among the institutional services; 7,699 individuals used those services in 2017 (a 69% increase on the 2009 figure of 4,569). According to the MoFSP records, there have been no unmet requests for a place with these care providers since 2010 (MoFSP, 2018).

The limitations in public-sector LTC coverage for people with disabilities and the elderly have led the private sector to enter this field. For the disabled, private provision of services is available, but the services are expensive and primarily located in metropolitan cities in very limited numbers.

Those individuals who are certified by a hospital report as in need of LTC and who cannot have care at home may receive care in a public institution or be funded for care in a private institution. For private facilities, monthly payment is the equivalent of twice the minimum wage and is paid to the institution. Eligibility requires means testing, where the incomes of all household members living together are taken into account. The MoFSP documents emphasise a preference for home care by family members, but there is no legal requirement for family members to care for their relatives at home. In 2017, 14,080 individuals received care at private institutions at a total cost of 400 million Turkish lira (TL) (EUR 83.5 million)¹ (MoFSP, 2018). It should be noted that day-care services are also provided in facilities operated by some municipalities and the MoFSP at no cost. There has also been non-governmental organisation (NGO) involvement in this area, some of it dealing with people with disabilities and some of it with the elderly.

Oglak et al. (2017) state that the LTC infrastructure is rather limited, and the elderly are usually taken care of within the family. Home care, in which family member carers are paid for services provided to persons with disabilities at home, was emphasised in the

¹ At the average exchange rate for March 2018 of 4.79 TL per euro.

2007 National Activity Plan for Elderly People and is strongly encouraged by the incumbent government. Disabled people on a low income can benefit from the home care services of a relative, who is paid by the government. The conditions of the programme are:

- A medical report by a hospital medical council stating that the individual is severely disabled (*ağır özürlü*) – with a disability level of 40% or above – or needs care in order to sustain their quality of life.
- The per capita income of the family is less than two thirds of the minimum wage.
- The carer has to be a relative of the dependent individual.

Applications are made to provincial offices of the MoFSP. As of January 2018, the payment is 1,085 TL (EUR 227) per month. The amount used to be adjusted in line with government employees' pay rises every 6 months; but from 2018 increases will be at the discretion of the MoFSP. The payment is considered a social benefit, and no social security contribution is paid: carers may pay their own social security premiums and have the work count towards their retirement. In 2017, approximately 500,000 households with disabled members received payments, and the annual cost was around 5.7 billion TL (EUR 1.19 billion) (MoFSP, 2018). In total, around 800,000 households have benefited since the programme began in 2007.

To support home care, the Ministry of Health (MoH) provides home healthcare services. The legislation describes healthcare services as diagnosis, treatment, follow-up and rehabilitation, including social and psychological consultations at home. According to the regulations, health professionals (basically physicians and nurses) working at family health centres are expected to offer home healthcare services, mainly in the form of rehabilitation, physiotherapy, post-operational care and social services. Thus, nurses are not specifically defined as a professional occupational group in the recent regulations.

An important component of LTC is the pool of carers and the policies that address their work-life balance. Benefits and social assistance for the carers of relatives are rather limited in Turkey, and – with the exception of government employees – workers cannot take leave to care for their elderly dependants.

In-kind benefits targeted directly at the elderly or designed to support their carers are few in number and not regular. The MoFSP conducts a number of training programmes. The Ministry and some municipalities provide certain day-care services in their facilities for those in need of care, but the services are rather limited. Households with disabled members also enjoy discounts on certain goods, such as water and electricity. There is no legislation in this area and the discounts are at the discretion of the municipality or private company.

We should note that the 2015 National Activity Plan for Elderly People set new goals for 2015 and 2020. It is recommended that multidisciplinary and interdisciplinary services should be offered in LTC facilities. A second goal is to set up all these services using a comprehensive approach, including preventive treatment and rehabilitation services (MoH, 2015). Also of note is that in the National Development Plan (2014-2018) issues related to ageing and care services are mentioned, emphasising the importance of institutional care capacity and active ageing. The 11th Five-Year Development Plan proposal includes the elderly as a subsection, and probably LTC will be part of the plan.

2 Analysis of the main long-term care challenges in the country and the way in which they are tackled

2.1 Assessment of the challenges in LTC

2.1.1 Accessibility

With its rapidly ageing population, Turkey has difficulty in coping with the surge in demand for care services. Lack of capacity in nursing homes is an ongoing problem, noted by Subaşı and Öztekin (2006) and Oglak et al. (2017).

The care needs of the disabled appear to be met without any waiting list for institutional care. This is largely because those who have a relative capable of providing care are channelled into the home care programme, where payment is made by the government to families. The programme faces various issues, because appropriately designed support systems are lacking.

Another issue regarding access is the non-take-up of services. Given the high prevalence of informality in the economy and the difficulty of means testing, it is likely that the system results in non-take-up, since the final decision is at the discretion of the administration. Indeed, in another programme that uses means testing – the free public health insurance programme – Erus et al. (2015) find non-take-up among low-income households with elderly or ill members to be 30%. A report by Parliament (TBMM, 2013) also finds discrepancies in the medical reports on the level of disability: since there is no standard procedure, two comparable individuals may receive different reports. The document also notes that payments for care should not be fixed, but should vary according to the severity of disability and the income of the household.

2.1.2 Quality

There is no required certification process in place for institutional care. There is also a shortage of trained high-quality personnel (healthcare, social workers, etc.) (Tatar et al., 2011). Training is lacking in the home care system, and hence it is difficult to argue that appropriate care is being provided. Bağcıvan et al. (2015) worked with 100 informal carers of neutropenic patients and found that although the general rules regarding cleanliness were known to the carers, there was poor awareness of other important rules (like giving a bath). Sabancıoğulları and Tel (2015) mention in their study that the majority of carers have difficulty in communicating with their patients. We are not aware of monitoring procedures regarding care provided by family members enrolled in the programme. Anecdotal evidence suggests that the unskilled female labour force dominates the sector of LTC for the elderly.

Carer 'burnout' can be a problem facing those who take care of elderly family members. In this regard, Boyacıoğlu and Kutlu (2017) showed effective models to decrease the burden of family members caring for their older people. Other problems include neglect and abuse. Generally speaking, the care responsibility should rest with the state and municipalities, in line with the recommendations of international documents; meanwhile family members should only have a support role.

2.1.3 Employment

The current system based on home care is likely to aggravate the problem of low female labour force participation in Turkey. Women are usually expected to be the carers for the elderly and disabled in the family. Indeed, according to the authors' calculations on the basis of the Labour Force Survey of Turkstat, 7.95% of female part-time workers gave 'caring for a family member' as the reason for part-time employment. That was stated as a reason for being out of the labour force by 0.69% of women—given the fact that women's participation to labour market in Turkey is very low, even such a small ratio

explains the situation of thousands of women. The Turkish Family Structure Survey by Turkstat and MoFSP found that in 2011, 32% of the elderly received care from their daughter-in-law, 27% from their spouse, 22% from their son and 20% from their daughter. Görgün-Baran (2005) states that in elderly care, 83.2% of the caregivers were women. In Tekin Önür's (2015) study, conducted among 177 carers of the elderly in Afyonkarahisar, a province in the Aegean region, women took more responsibility than men for looking after family members in need. Taşdelen and Ateş (2012) found that the majority of family members who took responsibility for caregiving were women, and almost half of the carers had at least one chronic condition. Combined with deficiencies in the LTC system, this hinders female labour force participation in several different ways.

To begin with, lack of carer leave (except for government officials) makes it difficult for women to work, even if the care needs are rather limited. It should be noted that, even if legislation were introduced to tackle this, it would still leave out a large proportion of the work force, due to significant informality.

Second, it is likely that some of the young female members of households drop out of school to provide care for the elderly and to receive home care payments (if eligible). Lack of education, in turn, will reduce their chances of joining the labour market in the future.

Third, the lack of adequate training programmes for carers reduces the chances of a long-term career in this area. It also has an adverse effect on the physical and mental well-being of caregivers. A number of adverse medical conditions have been reported in earlier studies (Yıkılkan et al., 2014; Kokurcan et al., 2015; Bozkurt-Zincir et al., 2014; Aslan et al., 2009). As such, the system is a long way from providing a long-term career for caregivers. Furthermore, social security provisions are lacking, since the payments are considered to be transfers and do not count towards social security; carers have to pay the premiums out of their own pocket if they are to contribute towards their retirement.

Finally, as mentioned repeatedly, informality is an important issue among caregivers. A recent report by the medical/health and occupational organisations in Turkey (Beyazit et al., 2015) declares that, regarding home care, caregivers' economic, occupational and social rights are largely lacking and should be protected by the public authorities. In the case of the home care programme, this is not official employment and is naturally limited to the lifetime of the dependant.

2.1.4 Sustainability

With an ageing population and growing demand for care services, sustainability is likely to be an important challenge. Capacity is already lacking and the social assistance system is already financially stretched to provide support to those in need. With weakening family ties, a larger proportion of the elderly is likely to need institutional care in the future.

2.1.5 Assessment of reforms

It is acknowledged in official documents that a rational, systematic and sustainable mechanism should be established to respond to all those in need in society. The 2007 National Activity Plan for Elderly People, updated in 2015, recognises the need for a comprehensive policy addressing most issues (MoH, 2015). Inspections of the quality of institutions are undertaken; these provide care service assessments, such as the MoFSP's

'care service of standard quality'.² The establishment of a standard assessment of all institutions nationwide is thought to be very useful in this regard.

That said, while awareness has increased over the past 5 years, no systematic plan has been implemented. The new development plan for 2019-2023 is being prepared and LTC issues have again been raised at meetings. Finally, work on old-age care insurance has been going on for some time.

2.1.6 Policy recommendations

The number of both rest homes and care and rehabilitation centres should be increased to help those who may not be able to provide care to relatives either temporarily or permanently. The quality of the services provided should be improved as well, and a certification procedure should be introduced to ensure sustainable quality.

Coordination should be established among different institutions providing support to the elderly and persons with disabilities.

While care provision by relatives at home may offer a solution to the increased need for services, it is clear that such a system requires a number of support mechanisms to work properly. An effective training system is necessary to ensure that the required care is provided, but also to offer carers a long-term career in the care sector. Social security provisions should be set up to ensure that carers can meet their retirement pension obligations and hence support themselves in their old age. Additionally, a set of assistance and support services should be devised, such as (i) assistance with self-care, (ii) residential support services, (iii) support in education for children with disabilities, (iv) communication support (through sign-language interpreters), and (v) assistance animals.

Lack of both paid leave and temporary institutional support (such as care during the daytime) possibly has a negative effect on the carer and on other household members who take the carer's place when he/she is absent.

3 Analysis of the indicators available in the country for measuring long-term care

Data on LTC needs are largely lacking in Turkey. The latest official survey on disabilities dates from 2002. Secondary sources, such as Turkish Family Structure Survey, provide limited information regarding LTC needs. Detailed and regular updates are necessary to evaluate the situation.

As to the capacity and use of LTC facilities, the MoFSP provides detailed information in its annual reports and monthly bulletins. The information, however, extends no further than the number and capacity of facilities. There are no published indicators on the quality of care. Nor is there any accreditation procedure in place. The number of beneficiaries of home care payments is also shared by the MoFSP regularly; yet, the number of applicants who have been turned down is unknown. The number of people on the waiting list for institutional care is not made public, but can be gleaned from the inquiries of MPs directed to the MoFSP. Thus, it is extremely difficult to make regular assessments of access, adequacy, quality and sustainability of the LTC system.

Regarding the labour market, the impact of caregiving on labour force participation and employment can be substantial, especially among young women. The Labour Force Survey by Turkstat contains questions on why an individual has been out of the labour force or has been working part time.

²http://eyh.aile.gov.tr/data/54732e16369dc54930f7ead4/D%C3%BCzeltimi%C5%9F%20BHKS%20Bidiri%20Kitap%C3%A7%C4%B1%C4%9F%C4%B1_son_FUAT.PDF p. 10. Accessed on 18 February 2018.

Finally, there is no evaluation of the home care programme, which covers about half a million households. An assessment of the programme, with an emphasis on the situation of disabled people, as well as carers, would be valuable in addressing problem areas of the programme.

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