ESPN Thematic Report on Challenges in long-term care

Romania

2018

Luana Pop
February 2018

EUROPEAN COMMISSION

Directorate-General for Employment, Social Affairs and Inclusion
Directorate C — Social Affairs
Unit C.2 — Modernisation of social protection systems

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European Social Policy Network (ESPN)

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The ESPN brings together into a single network the work that used to be carried out by the European Network of Independent Experts on Social Inclusion, the Network for the Analytical Support on the Socio-Economic Impact of Social Protection Reforms (ASISP) and the MISSOC (Mutual Information Systems on Social Protection) secretariat.

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Acronyms

LTC – Long-term care

MH – Ministry of Health

MLSJ - Ministry of Labour and Social Justice

NACRPA - National Authority for Children's Rights Protection and Adoption

NAPD - National Authority for Persons with Disabilities

NIS – National Institute for Statistics

NPPH – National Public Pension House

Summary

Starting in 2011, when long-term care (LTC) was for the first time defined in Romanian legislation (social assistance law L292/2011), a series of positive developments have been initiated. Unfortunately, LTC in Romania is still scattered among different sectors (health, social assistance, social protection of disabled people, social protection of children's rights, pensions), and the responsibility for the organisation and financing of LTC services is split between different ministries, national agencies and administrative levels (national/county/local). Overall, benefits and services targeting different groups in need of LTC fall under (a) social assistance policies (in the case of the frail elderly), (b) social protection of disabled people, (c) the public pension system (in the case of invalidity pensioners), and finally (d) the health care system (in the case of the chronically ill).

Scattered responsibilities and programmes, in the absence of effective coordination among sectors, agencies and administrative levels, have led over the years to a series of overlapping measures (due to a double system of assessing functionalities, for invalidity and for disability), inadequate coverage, uneven developments and unpredictability, and lack of sustainability/stability in funding.

The LTC system in Romania, as with the entire social protection system, is biased towards monetary benefits, with a deficit of social services, and especially those aimed at supporting independent living and deinstitutionalisation (i.e. rehabilitation, social integration, and medical preventive services). Thus, while the degree of institutionalisation is relatively low among the dependent population (2.5% in the case of disabled people, 0.4% in the case of the elderly), the demand for residential services is still very high compared with the supply, due to the insignificant amount of non-residential services provided (in 2016 only 0.3% of disabled people living with their families were covered by non-residential services). Most residential centres are, traditionally, placed in rural areas (and maintained from local budgets) while non-residential services are provided in big cities. Caregivers are mostly informally employed, despite the fact that there is a legal system in place permitting severely disabled people to opt for a formally employed caregiver or an equivalent indemnity (covering, in principle, 38% of the total number of accredited disabled people).

Most of these uneven developments are due to the fact that financing for almost all social services, including residential centres, was progressively decentralised over the last 15 years (whereas over 90% of local authorities are in rural areas, with an extremely low capacity to raise funds even for their own administration). Therefore, a very high proportion of social assistance and non-residential services developed lately are to be found in big or county residence cities, with residential centres condemned to underfinancing. It is impossible to estimate the total expenditure on LTC; but social assistance services are systematically underfinanced. Less than 1% of total state spending on social assistance goes on services – 99% takes the form of monetary benefits. In 2016, while overall social assistance expenditure increased in absolute terms by 18%, expenditure on social services decreased by 39%; thus the proportion of total expenditure on social services decreased from 0.6% in 2015 to 0.3% in 2016[1]. The proportion of public expenditure accounted for by total expenditure on private and public homes for the elderly decreased during 2012-2016 (Tables 9-11), transferring more costs to beneficiaries.

The legislative amendments of 2017 started to correct this situation (which was also responsible for a higher degree of informality among caregivers of severely disabled

[1] Ministry of Labour and Social Justice, Statistical Bulletin 2016 on Social Assistance (table 1, p.29), available at http://www.mmuncii.ro/j33/images/buletin_statistic/Asistenta_2016_fin.pdf.

people), by recentralising some expenditure and benefits, and taking over some co-payment responsibilities from the beneficiaries.

Despite the recent amendments, which will definitely enhance support for the objectives of the adopted national strategies, the administrative and professional capacity to support a complex and fast-growing LTC service network is still absent (due to understaffed communities, and low recognition and salaries for caregivers in both the public and private sectors). In addition to this, the educational system is far from supporting the need for professionals in this area, and from being able to integrate disabled people into the labour market. Employment policies are also weak and ineffective in addressing these issues. Finally, while decentralisation is welcomed in many respects, the radical financial decentralisation of social services led to uneven development and a lack of transparency (aggregate data on programmes and services financed from local budgets are mostly not available); thus stable financing mechanisms need to be put in place, in order to support a sustainable development of services, transparency, and predictability of financing.

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

Design of the long-term care (LTC) system. LTC is defined by the law on social assistance (L292/2011) as 'the care provided to a person who needs support for fulfilling daily life activities for more than 60 days. Long term care is to be ensured in people's homes, in residential settings, in day care centres, within the home of the service providers and within the community.' The personal services that may be offered are further described as: (a) medical care services; (b) rehabilitation and environment adaptation services, i.e. small adjustments, repairs, or other similar services; and (c) other rehabilitation services, i.e. kinesiotherapy, physiotherapy, medically recommended gymnastics, occupational therapy, psychotherapy, psycho-pedagogy, speech therapy and other forms of therapeutic recovery.

Romania does not yet have a coherent and well-coordinated institutional framework for LTC, targeting different groups in need (the chronically ill and frail elderly, invalidity pensioners, the disabled) from ***different social protection systems***. Thus, in Romania LTC is provided through: (a) the social protection system for ***disabled people*** (under the responsibility of the National Authority for Persons with Disabilities – NAPD[2], the National Authority for Children's Rights Protection and Adoption – NACRPA[3], the county-level Social Assistance Directorates, and the Ministry of Health – MH); (b) the social assistance system (targeting ***elderly people***), directly under the coordination of the social assistance department of the Ministry of Labour and Social Justice (MLSJ), with a series of services under the direct responsibility of local and county-level authorities (County Directorates for Social Assistance and Children's Rights Protection); (c) the public ***pension*** system (under the coordination of the National Public Pension House – NPPH, under the authority of the MLSJ); and finally (d) the health service system (under the MH and the National Health Insurance House (NHIH)). As a consequence, the institutional network of LTC providers is fragmented, and lacks coordination and stable funding mechanisms. During the last ten years LTC was systematically split between different sectors (social and health), different departments/ministries and different administrative levels (central/county/local). The two major pitfalls of this design are: (a) the stability and availability of funding (as some of the benefits/services are centralised and some decentralised) and (b) the lack of aggregate data/information in regard to the provision and availability of decentralised services/benefits.

[2] Reorganised in the beginning of 2015; formerly the Directorate for Persons with Handicap (DPH); the Authority functions within the Ministry of Labour and Social Justice.

[3] Both National Authorities come under the direct responsibility of the MLSJ.

In summary, while in many cases target groups for LTC overlap (the disabled, invalidity pensioners, the elderly) and some social protection measures overlap/compete, in most cases coverage is incomplete, insufficient or entirely missing.

Financing of LTC. The availability of effective financing mechanisms and the stability of financing are the most important challenges facing LTC in Romania. Financing of LTC is split between the state budget (responsible for most monetary benefits), the Social Insurance Fund (responsible for benefits of invalidity pensioners), the Health Insurance Fund (partially responsible for rehabilitation and in-home medical and palliative care services) and local budgets (mostly responsible for residential and non-residential institutional care, but also for general social assistance services). Financing of social services provided to the elderly and disabled has been progressively decentralised, thus making them unstable and vulnerable.

Most local municipalities are not prepared to take over cost-intensive social services (such as residential and non-residential institutions), as 90% of them are rural, with an extremely limited ability to raise funds (other financing sources, besides public ones and beneficiaries, are rather insignificant, about 1% or less of the total). Expenditure on homes for the elderly under the responsibility of local authorities is supported by beneficiaries in a higher proportion (30% in 2016 – a constant increase since 2012, see Table 10) than those under the responsibility of county councils, which have higher budgets and better access to state budget funds (see Table 9). Thus, most of the big investments and injections of finance have been made with European funds from the state budget, under a national rehabilitation programme. State budget subsidies have been rather limited over the last five years, the proportion of expenditure from this source decreasing constantly until 2016 (Tables 9-11). Without systematic financial support, social services provision is still limited and of inadequate quality.

While there are no data on expenditure by private service providers, data on private residential homes for the elderly are available (Table 11). In 2016, about 6.6% of their expenditure was from public sources (local and state budgets, a percentage which decreased from 13% in 2012); 74% was supported by beneficiaries; and 19% came from other sources (more than half of this from NGOs, and about one third from external funding).

The lack of transparency in regard to the funding of social assistance services from local/county budgets makes it even harder to draw any substantial conclusions; but the variability in financial and administrative capacity makes services very uneven across regions and communities. In addition, the *unpredictability of funding* is also a big concern for private providers (mostly NGOs), forcing many of these, who have extensive experience accumulated over the years, to close down or limit their activities.

Monetary benefits vs social services. The entire social assistance system is biased towards monetary benefits, and LTC is no exception to this. To begin with, while only 2.5% of the overall population registered as disabled are institutionalised, almost 15% of children with disabilities live in residential institutions or in placements (with professional maternal assistants or substitute families). While residential institutions are rather scarce and their quality low (mostly limited to caregiving institutions and protected shelters, see Table 6), the number of *non-residential services* for non-institutionalised disabled/frail elderly people is even lower, covering only 0.3% of this population, and 0.4% of the number of non-institutionalised severely and seriously disabled people. This might be one of the reasons for the high proportion of institutionalised children with disabilities. Thus, while between 96% and 98% of those non-institutionalised disabled people are covered by a series of monetary benefits (including transportation facilities and tax exemptions) very few disabled adults are active in the labour market (around 7% of disabled working-age adults, according to the national strategy for poverty prevention and social inclusion, p. 29) and even fewer – i.e. 0.4% - have access to specialised rehabilitation and support services (day centres, respite centres etc.). Deinstitutionalisation, while an important objective of most national programmes in the field of social protection, is hard to pursue in the absence of any effective network of support services.

Residential versus non-residential care. Thus, while 2.5% of the disabled, and only 0.4% of the population over 65 years, are in residential care (2016), institutionalisation is a common choice for families without the capacity to take care of their elderly, chronically sick or disabled members. The demand for institutions is really high, especially for the elderly population. During the last seven years, the number of public homes for the elderly has increased by 25%, while the number of private ones (which benefit from a low level of financial support from public sources, Table 11) increased almost five-fold, from 51 in 2009 to 245 in 2016. Overall, the average number of beneficiaries doubled over this period of time, reaching 14,500 in 2016. Non-residential services are scarce, covering less than 0.3% of the disabled living with their families, and in-home medical care and palliative services for the chronically sick fall well short of the actual needs and demand (Table 8).

Public specialised institutions for disabled people (including non-residential centres), but also homes for the elderly, are mainly the financial responsibility of local/county level authorities, with the MLSJ contributing through investment programmes (from European funds) and subsidies for service providers. However, starting in 2017 (Law GEO 51/2017) public institutions for the disabled will be entirely supported from the state budget (from VAT income). Beneficiaries are responsible for a small monthly contribution according to their income level. Elderly people are required to pay up to 60% of their personal income (but not more than the average monthly allowance established by the home); when an elderly person is not able to pay the whole monthly allowance, their family is required to sign a contract for the payment of the remaining or entire amount, depending on the case (a combination of out-of-pocket payments by the elderly person and by their family is more common). In cases where neither the elderly person nor their relatives/family has enough income, the contribution is paid entirely from local municipality budgets. This was also previously the case for disabled people in residential care. Although until 2017 the financial responsibility for institutionalised disabled people extended to 4th-degree relatives, Law GEO51/2017 changed this situation, leaving only the direct family (parents/children/spouses) financially responsible (this is mainly a financial responsibility of the legal guardians of dependent persons); local municipalities are responsible for any remaining amount. Severely disabled people and their families have no legal payment obligations.

Medical facilities and services, especially rehabilitation services for disabled and invalidity pensioners (but also all the costs related to the caregiver of severely disabled persons during hospitalisation) fall under the responsibility of the Ministry of Health. Systematic and well regulated in-home LTC services are mostly restricted to those provided by the (professional) personal assistants of the severely disabled (employees of local authorities) and to medical and palliative services provided to chronically ill people through the health insurance system. While the law allows the families of severely disabled people to hire or be hired as a personal assistant of the disabled person, the beneficiary (i.e. the disabled person or their legal guardian) can opt for a monthly indemnity (equivalent to the net minimum salary payable to the personal assistant) instead. Because these personal assistants (mostly women) were employees of the local authorities, paid out of local budgets, many city authorities pushed beneficiaries to opt for the indemnity, limiting in some cases the rights of family members to legally enter the labour market. Indemnities are not associated with any obligations or specific conditions on the use of the money by the beneficiary. Indemnities are cheaper for the local authorities: despite the fact that their value is equivalent to the net salary of a personal assistant, they relieve local authorities of the obligation to pay for additional social contributions or to provide replacement staff when personal assistants are on leave. While aggregate data are still not available regarding the mix between personal assistants and indemnities, or the proportion of elderly people among those assisted, evidence from many city halls suggest that the proportion of personal assistants decreased over time due to the financial decentralisation of the system. Starting in 2018, the salaries of personal assistants will be entirely supported from the state budget.

The proportion of elderly people in this scheme is not known, as data are not available. The only information on age structure relates to the total population of disabled people, of which 43.3% are over 65 years and another 11.1% between 60 and 64 years. Yet, while more than half of the disabled population is over 60 years old, the proportion of the institutionalised population is lower among the disabled elderly, dropping from an overall average of 2.3% to 1.3% for those over 60 years.

Formal and informal caregiving. Most caregivers of disabled persons work informally, paid by the family or supporting themselves, as in the case of many family members of disabled people, from the indemnities of the disabled person. While more than one third of disabled people living with their family are severely disabled (around 38% in 2016), not all of these benefit from formal caregiving, as many are forced to take up the indemnity instead. Non-residential care centers are too few to count. Caregiving in Romania is mostly an informal sector, with many people paying family members/relatives or hiring caregivers informally. This holds true for care services for the elderly, the disabled and children. The size of this informal industry is hard to estimate, but the practice was so widespread that in 2014 a law instituting the nanny profession was passed, and in 2017 the details of its implementation were finalized. The law tries to stimulate formal working relationships in the field of child care, by making child caregivers self-employed service providers (and not employees!). Overall, at most 30% of disabled people benefit from formally employed caregivers, while a rather insignificant proportion of caregivers for elderly are formally employed.

Eligibility evaluation. In Romania, there are two parallel systems of assessing an impairing health condition: the disability assessment system (with four degrees of impairment: severe/serious or marked/moderate/mild), with all the monetary and in-kind benefits deriving from it, and the invalidity assessment system (with four degrees of invalidity: first degree, the most severe one, to the fourth degree, the mildest one). Disability is assessed by commissions within local branches of the NAPD. The Social Assistance and Child Protection Directorates at county level are in charge of receiving and screening applications. As for the invalidity system, this is mainly under the responsibility of the NPPH (i.e. the National Institute for Medical Expertise and Regaining the Work Capacity), as it draws on social insurance pension benefits (invalidity pensions and rehabilitation services). Starting in 2007 there has been an interest in unifying the two systems according to the international classification system of functionalities. Both the National Authority for Disabled Persons and the National Institute for Medical Expertise reiterated their interest in a common system in 2016[4], yet no significant changes have occurred in recent years. The degree of invalidity/disability is the only eligibility criterion for obtaining certain benefits, to which a means-tested co-payment in the case of institutionalization is added.

Demand projections for LTC. While Romania was, in 2016, among the European countries with the lowest life expectancy/healthy life years at 65 years (see Eurostat database, tsdph220), according to the Ageing Annual Report 2018 (EU, November 2017) life expectancy is predicted to increase at a higher pace (along with that in other similar countries) over the next fifty years. Thus, the old-age dependency ratio is predicted to increase from 26.3% in 2016 to about 52% in 2070, while the percentage of the very elderly (over 80 years) compared with the overall working population is expected to increase from 6.4% (in 2016) to 24.4% in 2070 (Ageing Report 2018, p. 206). Yet Romania is not able to cope with even the most urgent needs of its current elderly population. In order to be able to cope with an even higher demand, Romania will have to invest not only in social services for the elderly or chronically sick, but also in the health of the future elderly and their opportunities in the labor market, as well as in education and labor market support for disabled persons.

[4] http://anpd.gov.ro/web/o-noua-abordare-a-dizabilitatii-criterii-armonizate-de-evaluare-in-vederea-incadrarii-in-grad-si-tip-de-handicap-si-in-grad-de-invaliditate-2/.

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

2.1 Main challenges of the LTC system in Romania

Access to and adequacy of LTC. The coverage of the LTC target groups with monetary benefits is high (around 98%) as most of these benefits are categorical and access is automatically granted by the disability certification. Yet, while LTC services are needs-based, access is *de facto* restricted by several factors – scarcity of services, availability of day care and support centres (mostly restricted to urban areas/big cities), and the payment capacity of the family.

Institutions for the elderly and disabled are scarce; homes for the elderly have increased in number during the last seven years, doubling the number of beneficiaries. The highest increase was in the number of private homes for the elderly (an almost five-fold increase, from 51 in 2009 to 241 in 2016). The number of public homes for the elderly is half the number of private ones, 123 in 2016 compared with 246 private homes. But pending applications as a proportion of total capacity - for both private and public institutions – decreased from about 40% in 2009 to about 13%-14% in 2016, reflecting a rather constant 'active demand' for institutionalisation. This is not necessarily determined by a relatively low and constant need for residential care, but by the high costs associated with it. Thus, despite a significant need for residential care (in the absence of other day care and in-home solutions), the active demand seems rather constant, and shaped by the high costs associated with emerging (private) residential solutions.

Access to residential institutions is thus also limited by the payment capacity of the family or legal guardian. Public institutions, for both the disabled and the elderly, require a co-payment. The family[5] signs a financial contract with the institution and, depending on the income of the person/family, a monthly fee corresponding to an average daily allowance established by the institution is supported by the beneficiary. Yet the payment is means-tested and in the case of a lower income per family member the local/county council is responsible for the payment. As many public residential institutions are placed in rural areas, we can assume that access to these services could have been restricted by the lack of financial capacity of the families and local authorities. Starting with 2018, the financial responsibility of local authorities is being taken over by the state budget.

Medical and palliative in-home care services, contracted through the NHIH, have developed only recently, as the legislation regarding the contracting and reimbursement of private providers of in-home medical services has only been refined during the last five years. All other social assistance in-home services are provided by private NGOs (which benefit from subsidies from the state/local budgets) or public local authorities, accredited as service providers. But as in the case of many other social services, these are mostly provided in cities and towns; those covering rural areas are rather scarce due to lack of financial and professional capacity. Access to social assistance services is partially restricted by the fact that these are provided in bigger cities/county residence city, and less so in smaller cities and rural communities.

In conclusion, very few services are provided within smaller communities, and there is a chronic lack of prevention, early detection and specialised support services, especially in rural/marginalised/remote communities. The integrated community centres, expected to develop during 2017-2018 (initially within a pilot programme funded with European money, i.e. from the ESF), will take over this liaison function while emphasising the medical basic prevention activities (community nurses/health mediators).

[5] Until recently the financial responsibility for disabled people in residential care extended to relatives of the 4th degree.

Quality of LTC services. The quality of social assistance services is regulated through Law 197/2012, which defines the process for accrediting social service providers. According to the 2015 amendments to the law (D27/2015), the responsibility for accrediting and granting licences to social service providers falls to the different specialised agencies of the MLSJ (National Agency for Disabled Persons, National Agency for Children's Rights Protection). The framework for the classification, organisation and functioning of social services was also established in 2015 (through D 867/2015).

All social service providers can be found in the electronic register of social assistance services providers (MLSJ D280/2006) and are supposed to comply with the minimum standards required for each type of service in order to be accredited. These are regulated by ministerial orders (Order 2126/2014 regarding the minimum standards for social services providers for the elderly, Order 1343/2016 regarding the minimum standards and financing procedures of residential care units for the elderly, and Order 67/2016 regarding the minimum standards for social services providers for the disabled). Due to these new regulations, after a peak of accreditation and issuing of licences in 2016 (in December 2016, 2,947 providers were licensed, of which 1,003 were for residential long-term centres, 586 for temporary residential centres, and 663 for day centres), many centres lost their accreditation. In January 2018, there were only 2,494 accredited social service providers, of which 232 were residential care providers for the elderly (106 public and 126 private) and 207 were in-home care service providers (38 public and 169 private)[6]. This situation was due to the legal provision (under the 2012 law) limiting the ability of a social service provider to reapply for a licence for two years after their accreditation was automatically removed (due to non-activity). This situation was reconsidered by the 2017 amendment, as in July 2017 about 600 social service providers were blocked by this limitation (according to the MLSJ) and currently (March 2018) a new draft amendment to the 2012 law is under public scrutiny[7].

The proportion of medical staff in most of the institutions for disabled people varied from 62% (for social integration centres) to 69% (for rehabilitation centres) in 2016: but the proportion of professionals will have to increase to 80%, according to the Law GEO60/2017. Increasing the proportion of medical staff/professionals is still a challenge, especially in the case of homes for the elderly (many of which are placed in rural areas), which do not reach the legal minimum threshold of 60% (according to the MLSJ). In 2016 the importance of good-quality services was reiterated by the government through the approval of the methodological norms for the national programme for improving the quality of life of persons in elderly homes (Order 1343/2016 of the MLSJ). While the average number of beneficiaries per residential centre has decreased during the last seven years, residential centres for disabled adults are still more crowded compared with homes for the elderly.

Overall, despite the constant refinement/updating of norms and quality standards, from professional standards to expenditure levels, the quality of most services, especially residential ones, is extremely low. The lack of funding leads to a lower-than-allowed proportion of specialised staff (who are systematically underpaid). Most of the facilities are old and underfunded; and the national rehabilitation programmes of some residential social services have not proved enough to overcome these shortages. There are no signs that the quality of these services has improved over time. In fact, most of the services are oriented towards care, and less towards counselling, rehabilitation and prevention. And this is despite the constant discursive emphasis of the MLSJ and of the national strategies/programmes on treating deinstitutionalisation and residential care as the last resort and alternative to home care.

[6] http://www.mmuncii.ro/j33/index.php/ro/2014-domenii/familie/politici-familiale-incluziune-si-asistenta-sociala/4848.

[7] http://www.mmuncii.ro/j33/images/Documente/Transparenta/Dezbateri_publice/2018_03_06_EM_197.pdf.

Employment challenge. As most of the disabled (due to low activation services for this segment) and many elderly people are highly dependent on their families, family members provide an important amount of unpaid or informal work. While data do exist on the proportion of severely disabled people opting for personal assistants, most of them are under the care of a family member. The same holds true for the fragile elderly. For elderly people, besides in-home care services provided to those in need (mostly to those without a family, who live by themselves), there was, until recently, no legal framework to formally recognise the work of informal caregivers.

The 2017 amendment to the law regarding the social protection of disabled people (GEO 51/2017) facilitates access by the caregivers of severely disabled people to formal employment; in addition, it re-enforces the legal right of families with dependent elderly members to request part-time working from their regular employer, and to receive a part-time salary (and employment rights) for caregiving from the local authority. While this right was stipulated by the 2000 law regarding social assistance to the elderly (Law 17/2000), it was never implemented, mainly for financial reasons.

Data on informal care are scarce; the main data source (Eurostat, LFS, 2010-2012, module on work-life balance) suggests that the lower overall employment rates for women (compared with men, but also with the European average), are not necessarily determined by caring responsibilities. In 2010, the proportion of women declaring that they take care of a relative aged 15 or over was lower than the European average, while the proportion of men was higher than the European average. Yet the proportion of *employed women* taking care of a relative is far higher than the European average.

The new trend towards financial recentralisation will surely stimulate the formalisation of caregiving; but the quality of care, and the support to improve this, are still extremely low. Jobs in this sector are low paid (less than the salary of a nursing aid; and, starting from 2018, the difference in pay between caregivers and medical support staff will increase dramatically); and caregivers are not required to have a specific qualification. While possession of a qualification is an advantage (and many private life-long education providers offer courses and EU-recognised certification), it mostly represents a ramp towards working abroad. Caregivers are either employed by service providers for in-home care, or are working in the family, employed by the local authorities (in both cases they are working as employees); both categories of employees are supposed to receive constant and systematic professional support, in the form of skills-building and short-term specialisation courses. However, professional support and networking is, in most cases, insufficient compared with the needs of caregivers and in relation to the minimum quality standards stipulated for this occupation.

Financial sustainability challenge. The most important challenges of the LTC system are related to its financing. The financing of LTC is split between various sectors and ministries/agencies (health, social protection, child protection, social protection of the disabled, education) and administrative levels (state budget, county-level budgets and local budgets). While the scattering of financing sources can be easily overcome with proper coordination, the capacity of local budgets to pay for benefits (especially social services, which are labour intensive) is rather low; therefore, the progressive decentralisation of social services, and of some monetary benefits as well, led to a chronic lack of funding, and, ultimately, to a degrading of social services. The 2017 amendments will partially reverse this trend.

While there is no systematic information and synthetic data on the expenditure on most of the residential and non-residential centres for the disabled, or the total expenditure on in-home care (besides medical and palliative in-home care financed through the NHIH), the effects of financial decentralisation can be illustrated by reference to the homes for elderly. Those homes under the responsibility of local authorities have the lowest proportion of state subsidies (decreasing from 12% in 2012 to 2.6% in 2016), followed by the private ones (with a decrease from 7.3% in 2012 to 3.6% in 2016); the decrease

in state subsidies correlates with an increase in beneficiaries' contributions, from 26% in the case of public homes under the responsibility of local authorities in 2012 to 30% in 2016; for private homes, beneficiaries' contributions have increased from 56% to 74% over the last four years (Tables 9-11). The wealthiest homes are the public ones under the responsibility of a county council (as county budgets have a higher capacity to sustain costs), with a contribution by beneficiaries of 17%, and relatively constant state budget subsidies of 5%-6%. Unpredictability of funding is a consequence of the decentralisation of public services and of the policy of state budget subsidies. Data show that private homes, followed by public ones under the responsibility of local authorities, exhibit the lowest expenditure per beneficiary. Costs might not reflect the quality of services provided, but might also be related to administrative efficiency.

In conclusion, the under-financing and unpredictability of funding are the most important challenges for LTC services. Yet, the new 2017 amendments try to limit the responsibility for co-payments to the immediate family of the dependent person, and provide the state budget to take over all expenditure on severely/seriously disabled people. This is a first step towards a recentralisation of costs, in order to ensure a minimum level of protection.

2.2 Recently planned reforms and policy recommendations

Recent amendments to the laws regulating LTC relate to: education and employment opportunities for disabled people; monetary benefits for formal caregiving to disabled people; and the recentralisation of some of the expenditure on social services. In terms of monetary benefits, these have been restricted to the social reference index (SRI), although this has not changed in value for the last seven years (Tables 3 and 4). Sanctions for employers with over 50 employees have been toughened and some restrictions imposed (see previous Section on employment challenges). But perhaps the most significant changes brought about by these amendments are those related to the financing of some monetary benefits and social services. These signal a reversal of the financial decentralisation process and an interest in identifying a stable financing mechanism for LTC services. While there is an important emphasis in government policy on deinstitutionalisation of disabled people, the availability of support services for dependent persons living with their families is far from meeting the actual needs and demands. Part of the problem is their financing. But in addition to this, the 2012 law regulating the quality of social services is also responsible. Adoption of the legal documents implementing the 2012 law on the quality of social assistance services (i.e. a series of orders of the MLSJ, adopted during 2014-2016, which establish the minimum standards for service providers for elderly and disabled people in residential and non-residential care – see further in Section 3) led to a crisis in accreditation; many providers lost their licences due to the changes and, according to the previous law, they are not allowed to re-apply for accreditation for two years after being suspended. An emergency ordinance in 2017 (GEO 51/2017[8]) amended the accreditation law in order to permit service providers to reapply immediately for a licence, and a draft amendment to the same law is currently (March 2018) under public scrutiny, designed to fix implementation problems which emerged during the last four years[9] (see also the Section on quality challenge).

But despite these latter positive developments, the general crisis in the LTC system has to be addressed more broadly, by developing as far as possible the professionalisation of those supporting and caring for dependent persons. A system of recognising informal skills in this area is essential, and mechanisms for promoting professionalisation and

[8] http://www.mmuncii.ro/j33/images/Documente/Legislatie/OUG51-2017.pdf; see also the justification note of the ministry regarding this GEO, available at http://gov.ro/ro/guvernul/procesul-legislativ/note-de-fundamentare/nota-de-fundamentare-oug-nr-51-30-06-2017&page=76.

[9] http://www.mmuncii.ro/j33/images/Documente/Transparenta/Dezbateri_publice/2018_03_06_EM_197.pdf.

stimulating jobs in this sector are crucial. Subsidising social service providers follows a first-come-first-served logic; along with low levels of subsidy, this does not stimulate certain services according to policy priorities. Thus, a mechanism for prioritising and differentiating subsidies would be welcomed.

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

Availability of data depends on the target group (the disabled, the elderly, invalidity pensioners, children), the ministry/agency responsible for the programmes/services, and the administrative level at which financial responsibility is placed.

Data on LTC for the elderly. This is an area for which data is available only in regard to residential care (public and private). Data regarding the number of facilities (public and private), average number of beneficiaries, capacity, pending applications, and financing by sources are provided by the National Institute for Statistics, through the TEMPO-online database[10] and the MLSJ (Statistical Bulletin, starting with 2016, 31A-31C). The statistical bulletins of the MLSJ[11] provide in addition information on subsidies for the rehabilitation of homes for the elderly within the national programme 'improving the quality of life of the elderly living in homes' (tables 26-27 therein). The MLJS also provides data regarding accredited social assistance services (including those addressing dependent persons living with their family (see tables 27, 28, 30, 32A, 32B).

Data on LTC for the disabled. Data regarding monetary benefits for disabled people paid from the state budget are provided by the MLSJ (quarterly statistical bulletin), yet data on one of the most important benefits, the personal assistant (or the equivalent indemnity) for the severely disabled, are entirely missing, as the benefit was – until 2018 – paid from local budgets. This information would have been crucial to assess the access of caregivers to the labour market. This is expected to change as the benefit will now be entirely supported from the state budget. This is a more general problem, as data – and especially financial data – regarding benefits and services financed by and under the responsibility of the local/county-level governments are entirely missing (with the exception of residential homes for the elderly). This is the case for all residential and day care centres for the disabled. While statistics regarding their number, beneficiaries and capacity are provided, there is no information regarding the expenditure on these services.

Data on LTC for the chronically/long term sick. In-home medical and palliative care are the only in-home services for which distinct data are provided[12]. The reports provide data on the number of contracted services, annual number of beneficiaries, and number of days of service provided by these. Until recently reimbursement was based on the number of specific services provided, thus not permitting an overview of the actual number of average days of service provided per beneficiary. Since 2015 these data are available; but there are no systematic data on in-home services for the elderly, as these fall under general social assistance services. For these latter ones, there are no data regarding their actual involvement (expenditure, number of beneficiaries, areas covered, specific services etc.).

Overall, the only quality indicators for assessing social services are those provided by the minimum quality standards for the various types of services and used to accredit service providers. For example, Order 2126/2014 of the MLSJ sets the framework for the

[10] http://statistici.insse.ro/shop/, ASS113B-ASS113E.

[11] Available at http://www.mmuncii.ro/j33/index.php/ro/transparenta/statistici/buletin-statistic.

[12] National Health Insurance House, annual activity reports, available at http://www.cnas.ro/page/rapoarte-de-activitate.html.

minimum quality standards of residential and in-home care for the elderly[13]. Order 1343/2016 of the MLSJ[14] reiterates the importance of setting and enforcing minimum quality standards for in-home and residential care for the elderly (within the national programme: 'the growth of the life quality of elderly in residential care'). Order 67/2015[15] sets standards for services for the disabled, while in February 2018 a draft setting out minimum standards for the care of disabled persons by professional personal assistants was posted for public debate on the site of the MLSJ[16]. Indicators mostly specify the tasks to be performed under various services, and by various type of professionals, thus providing an important way to define certain emerging occupations within LTC. Yet these indicators are not collected systematically and aggregated, as they are instead used as a check-list to accredit services.

Indicators to assess the financial sustainability and predictability of social services (one of the important challenges of the Romanian LTC system) are unavailable, due to mixed financing mechanisms and due to the fact that these fell, until recently, mostly under the responsibility of local authorities. For example, one of the few available indicators is the level and structure of expenditure on homes for the elderly. Overall costs for medical and palliative in-home care are available as well.

While administrative data are crucial, most of the European data on dependent persons are survey-based. Survey-based data (regarding elderly and disabled people – needs, health condition) are not available in the online database of the National Institute for Statistics (TEMPO-online), with the exception of a more general indicator (provided through Eurostat as well) regarding perceived health condition. While data provision has improved significantly during the last five to ten years, the availability of data depends on the ministry/agency and administrative level responsible for providing/financing the benefits/programmes/services.

[13] See Annexes 1, 2 and 8, available at http://www.mmuncii.ro/j33/index.php/ro/2014-domenii/familie/politici-familiale-incluziune-si-asistenta-sociala/3592.

[14] Available at http://www.mmuncii.ro/j33/images/Documente/Legislatie/O1343-2016.pdf.

[15] Available at http://www.mmuncii.ro/j33/index.php/ro/2014-domenii/familie/politici-familiale-incluziune-si-asistenta-sociala/3708.

[16] Available at http://www.mmuncii.ro/j33/images/Documente/Transparenta/Dezbateri_publice/13022018_Ordin_standarde_calitate_APP_28_nov_-2017.pdf.

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Annex

Table 1 Demand for social services for persons with disabilities (data provided by the NAPD)

	2016	September 30, 2017
Grand total	**786,546**	**791,761**
Living in the family, of which:	***768,456***	***773,773***
adults	706,401	729,132
children	62,055	62,629
Living in the family, of which:	***768,456***	***773,773***
severely disabled	289,511	298,629
marked disability/seriously disabled	406,688	403,703
moderately disabled	82,675	81,593
mildly disabled	7,672	7,746
In residential care, of which:	***18,090***	***17,988***
adults	18,079	17,988
children	11	

Data source: MLSJ, Statistical Bulletin, Social Protection of Disabled Persons (http://www.mmuncii.ro/j33/images/buletin_statistic/03012018-pers-dizabilitati-trim-III.pdf).

Table 2 Type and level of monetary benefits for disabled adults, children and their caregivers 2016-2017 (LEI)

	2016	2017	Notes
Child allowance for children with disabilities	200	200	Since July 2015
Child allowance for children with disabilities placed in family care	900	900	Since December 2014
Child-rearing indemnity for parents with children with disabilities between 3-7 years taking leave	450/1063	1063	Since July 2016
Support for active parents with disabled children requesting part time work programme	50% of the minimum child-rearing indemnity (85% of the minimum gross salary)		Since July 2016
	532	617	
Monthly food indemnity for persons with HIV/AIDS:			
adults	13-16 Lei/day	16 Lei/day	Changes have been in place from October 2016
children	11-15 Lei/day	15 lei/ day	Changes have been in place from October 2016
Monthly food allowance for HIV/AIDS disabled children	11-15 Lei/day	15 Lei/day	
Monthly indemnity for adults who are:			
severely disabled	234	234	
seriously disabled	193	193	
Complementary budget for all persons who are:			
severely disabled	106	106	
seriously disabled	79	79	
moderately disabled	39	39	
Indemnity for the person who accompanies a severely visually disabled person	969	1065	Starting in 2018, the value will equal the net minimum salary

***Data source**: Legislation*

Table 3 Changes in monetary benefits/level of benefits for disabled adults, children and their caregivers starting January 2018 (% of the SRI)

	From January 2018	From July 2018
Support for parents raising a child who is*:		
severely disabled	50%	60%
seriously disabled	30%	35%
moderately disabled	10%	12%
Monthly indemnity for adults who are*:		
severely disabled	65%	70%
seriously disabled	50%	53%
Complementary budget for all persons who are*:		
severely disabled	25%	30%
seriously disabled	20%	22%
moderately disabled	10%	12%
Personal assistant for persons (adults and children) with severe disabilities or an equivalent indemnity (with a net salary):		
gross (lowest to highest gradation, according to the number of years worked as a personal assistant)	1,900 Lei - 2,250 Lei	
net	1,162 Lei - 1,358 Lei	

** As a percentage of the SRI (social reference index, with a value of 500 Lei since 2008)*
Data source: *GEO 60/2017, GEO 51/2017, L153/2017.*

Table 4 Number of beneficiaries of monetary benefits for disabled people

	2012	2013	2014	2015	2016	30-Sep-17
Increased child allowance for children with disabilities:	**58,937**	**60,035**	**59,971**	**60,370**	**63,150**	**62,303**
under 3 years	*6,281*	*5,405*	*4,755*	*4,394*	*4,884*	*4,045*
over 3 years	*52,656*	*54,630*	*55,216*	*55,976*	*58,266*	*58,258*
Child-raising benefits for parents with a disabled child:						
child-raising leave/indemnity for parents with children less than 3 years, of which:	**247**	**1,707**	**3,965**	**3,644**	**3,403**	
received the minimum flat rate indemnity of 600 RON	**52**	**674**				
all support indemnity for parents with disabled children and for parents with disabilities, of which:	***6,995***	***7,873***	***8,497***	***8,566***	***8,644***	***8,883***
monthly allowance for children in residential care (family or institutional)				4,826	5,129	5,222
Monthly food indemnity for people with HIV/AIDS	**7,800**	**8,449**	**9,003**	**9,441**	**9,885**	**10,294**
Children	*176*	*165*	*176*	*247*	*253*	*244*
Adults	*7,624*	*8,284*	*8,827*	*9,194*	*9,632*	*10,050*
Monthly food allowance for children with HIV/AIDS disabilities					*181*	*183*
Monthly indemnity for adults with a severe or serious disability	**542,156**	**552,143**	**565,990**	**597,779**	**617,394**	**632,043**
Severe disabilities				**226,685**	**239,461**	**249,942**
Serious disabilities				**371,094**	**377,932**	**382,101**
Personal complementary budget for severely, seriously and moderately disabled (children and adults)	**658,677**	**671,143**	**681,279**	**716,566**	**739,794**	**761,273**
Severe disabilities				**257,783**	**271,342**	**285,260**
Serious disabilities				**383,549**	**390,370**	**396,573**
Medium (average) disabilities				**75,234**	**78,082**	**79,440**
Monthly indemnity for the companion of persons with severe visual disability	**43,818**	**43,836**	**43,252**	**41,546**	**41,529**	**41,433**

Data source: MLSJ, Statistical Bulletin (http://www.mmuncii.ro/j33/index.php/ro/transparenta/statistici).

Table 5 Number of social services for disabled adults (facilities and average number of beneficiaries)

	2016	
	No. of facilities	Annual average no. of beneficiaries
Total	**448**	**20,693**
Residential centres	**388**	**18,090**
Centres for caregiving	115	6,510
Protected shelters	115	914
Centres for social integration through occupational therapy	17	1,112
Centres for recuperation and rehabilitation:		
pilot centres	3	217
for neuropsychiatric issues	67	6,005
for disabled persons	64	3,245
Training centres for independent living	2	20
Respite centres	3	19
Crisis centres	2	48
Non-residential services	**60**	**2,603**
Day centres	22	1,054
Centres with occupational profile	1	29
Neuro-motoric recuperation centres – ambulatory	28	1,323
Mobile teams	1	-
In-home services	2	45
Psycho-social integration counselling centres	6	152

Data source: *ANPD.gov.ro/ statistics.*

Table 6 Demand for elderly care 2016

2016	Number	Percentage of total population
Population	**19,703,494**	
Population over 65 years	3,466,786	17.6
65-74 years	1,889,178	9.6
75 and over	1,577,608	8
Rural	9,119,228	
Urban	10,584,266	
Population with a perceived bad and very bad health condition (total population)	**1,438,355**	**7.3**
65-74 years	247,482	13.1% of the same age group population
75 and over	413,333	26.2% of the same age group population
Rural	711,300	7.8% of rural population
Urban	709,146	6.7% of urban population
Population affected by a health problem for at least 6 months during previous year	**375,411**	**26.10**
65-74 years	139,333	56.30% of the same age group population
75 and over	304,627	73.70% of the same age group population
Rural	195,607	27.50% of rural population
Urban	176,577	24.90% of urban population
Population with a chronic health condition or invalidity	**72,079**	**19.20**
65-74 years	37,480	26.90% of the same age group population
75 and over	96,567	31.70% of the same age group population
Rural	38,730	19.80% of rural population
Urban	33,020	18.70% of urban population

***Data source**: NIS, Tempo-online: CAV103J, CAV103L, CAV103B, CAV103H, POP106A (http://statistici.insse.ro/shop/?page=tempo1&lang=ro).*

Table 7 Number of public and private homes for the elderly, and of beneficiaries: 2009-2016

	2009	2010	2011	2012	2013	2014	2015	2016
Public homes								
Number	**98**	**88**	**95**	**108**	**103**	**105**	**118**	**123**
Capacity	6,577	6,438	6,400	7,854	6,941	7,019	7,693	7,630
Monthly average beneficiaries	5,875	5,587	5,211	6,485	5,761	5,892	6,615	6,488
No. of pending applications	2,726	2,834	2,417	1,773	2,936	2,379	2,797	1,017
Private homes								
Number	**51**	**63**	**80**	**95**	**126**	**141**	**194**	**246**
Capacity	1,690	2,160	3,061	3,730	5,075	5,601	7,778	9,659
Monthly average beneficiaries	1,504	1,957	2,668	3,057	4,064	4,657	6,530	8,102
Total number of homes for the elderly (public and private)	**149**	**151**	**175**	**203**	**229**	**246**	**312**	**369**
Total number of beneficiaries	**7,379**	**7,544**	**7,879**	**9,542**	**9,825**	**10,549**	**13,145**	**14,590**

Data source: *NIS, Tempo-online, ASS113B (http://statistici.insse.ro/shop/)*

Table 8 In-home care, 2016

	2016
Number of contracts with service providers	**498**
In-home medical services	489
In-home medical and palliative services	8
In-home palliative services	1
In-home medical care	
Number of decisions issued	**57,791**
Number of days according to the decisions issued	1,299,805
Number of beneficiaries	***45,116***
Number of actual days paid by the NHIH	1,116,907
Amount paid	58,076,160
In-home palliative services	
Number of decisions issued	**93**
Number of days according to the decisions issued	7,072
Number of beneficiaries	***93***
Number of actual days paid by the NHIH	3,588
Amount paid	224,340
Total number of beneficiaries	**45,209**

Data source: National Health Insurance House, annual report (http://www.cnas.ro/page/rapoarte-de-activitate.html).

Table 9 Number and financing structure of homes for the elderly under the responsibility of county councils

	2012	2013	2014	2015	2016
Number of homes	**37**	**34**	**31**	**44**	**45**
Number of places in homes	2,648	2,004	1,814	3,016	2,796
Average number of monthly beneficiaries	2,051	1,550	1,468	2,494	2,262
Number of pending applications	193	351	57	467	419
Average cost/beneficiary (LEI)	**2,156**	**2,428**	**2,460**	**2,852**	**3,050**
Financing structure					
From the local/county budget (%)	***78.1%***	***76.7%***	***79.0%***	***80.2%***	***77.8%***
County budget				31.3%	
Local budgets				48.9%	
Subsidies from the state budget (%)	***5.7%***	***5.5%***	***2.9%***	***5.9%***	***5.1%***
Beneficiaries' contributions (%)	**15.2%**	**17.2%**	**18.1%**	**13.5%**	**16.8%**
Other sources	**1.0%**	**0.5%**	**0.0%**	**0.4%**	**0.2%**

***Data source**: NIS, TEMPO-online database, ASS113E.*

Table 10 Number and financing structure of homes for the elderly under the responsibility of local councils

	2012	2013	2014	2015	2016
Number of homes	**71**	**69**	**74**	**74**	**78**
Number of places	5,206	4,937	5,205	4,677	4,834
Average number of monthly beneficiaries	4,434	4,211	4,424	4,121	4,226
Number of pending applications	955	831	850	940	598
Average cost/beneficiary (Lei)	**1,367**	**1,498**	**1,652**	**1,828**	**1,963**
Financing structure					
From the local/county budget	***60.3%***	***57.1%***	***57.1%***	***55.6%***	***66.4%***
County budget			9.0%	1.8%	4.6%
Local budgets			48.1%	53.8%	61.8%
Subsidies from the state budget	***12.0%***	***13.2%***	***10.2%***	***12.7%***	***2.6%***
Beneficiaries' and legal guardians' contributions	***26.4%***	***28.5%***	***29.2%***	***30.5%***	***29.9%***
Other sources	1.4%	1.4%	3.6%	1.3%	1.2%

***Data source**: NIS, TEMPO-online database, ASS113C.*

Table 11 Number and financing sources of private homes for elderly

	2012	2013	2014	2015	2016
Number of homes	**95**	**126**	**141**	**194**	**246**
Number of places	3,730	5,075	5,601	7,778	9,659
Average number of monthly beneficiaries	3,057	4,064	4,657	6,530	8,102
Number of pending applications	1,461	1,754	1,472	1,390	1,375
Average monthly cost/beneficiary (LEI)	**1,514**	**1,731**	**1,560**	**1,641**	**1,755**
Financing structure					
From local/county budgets	***5.8%***	***5.7%***	***4.2%***	***3.4%***	***3.0%***
Local budgets			*2.2%*	*1.6%*	*1.1%*
County budgets			*2.0%*	*1.8%*	*1.8%*
State budget subsidies	***7.3%***	***6.8%***	***6.7%***	***5.0%***	***3.6%***
Total public funding	**13.1%**	**12.5%**	**10.9%**	**8.4%**	**6.6%**
Beneficiaries' and legal guardians' contributions	***56.1%***	***55.6%***	***63.8%***	***68.0%***	***74.3%***
NGO funds	***18.5%***	***21.4%***	***14.0%***	***13.2%***	***10.5%***
External funding	***7.7%***	***6.6%***	***8.5%***	***5.0%***	***5.7%***
Other sources	***4.6%***	***3.9%***	***2.8%***	***5.3%***	***3.0%***

Data source*: NIS, TEMPO-online database, ASS113D.*