

22 January, Berlin

German Institut for Human Rights

Normative Elements

Key elements on the topics of long term care,
palliative care and autonomy and independence

LONG TERM CARE

from EU law perspective

- LTC is expressly mentioned in **The European Pillar of Social Rights** proclaimed by the European Parliament, the Council and the European Commission at the Social Summit for Fair Jobs and Growth in Gothenburg on 17 November 2017. This proclamation reflects the unanimous support by all EU institutions for the principles and rights under the Pillar. Its realization is a joint responsibility of EU institutions, MS, EU institutions, social partners and other stakeholders. EU institutions “will set the framework, implementation of the Pillar through legislation where needed, in full respect of MS competences and taking into account its diversities”. The European Pillar of Social Rights is about delivering new and more effective rights for citizens. It builds upon 20 key principles, structured around three categories: equal opportunities and access to the labour market, fair working conditions, **social protection and inclusion**. The visibility given to LTC in the Pillar opens opportunities to develop “a more ambitious action plan at the EU level to respond to the growing common challenges”.

The European Pillar of Social Rights Chapter III: Social protection and inclusion

18. Long-term care

Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.

- LTC is included in **the proposal for revision of Regulation 883/2004 on social security coordination**, presented by the Commission in 2016. This Proposal seeks to establish a closer link between where social contributions are paid and where they are being received. It also provides better tools for cooperation between Member State authorities and covers **new aspects such as long-term care**. The revision aims to establish **a coherent regime for the coordination of long-term care benefits** (currently dealt with under the sickness chapter) by introducing a separate Chapter for their coordination in Regulation (EC) No 883/2004, by including **a definition and providing for a list of those benefits**. The new rules will provide more legal certainty to the growing group of people who, in our ageing societies, rely on long-term care. In relation to the coordination of long-term care benefits, a majority of Member States supported the creation of a specific definition and/or specific chapter and/or list of

benefits, whilst others were in favour of the status quo. The results of the 2012 public consultation highlighted a diversity of opinions regarding the Member State competent for providing long-term care benefits.

Proposal for REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL amending Regulation (EC) No 883/2004 on the coordination of social security systems and regulation (EC) No 987/2009 laying down the procedure for implementing Regulation (EC) No 883/2004 – COM(2016) 815 final [please find attached]

Newest version (now in the Council – first reading)

Recital 24 is replaced by the following:

"(24) Long-term care benefits for insured persons and members of their families need to be coordinated according to specific rules which, in principle, follow the rules applicable to sickness benefits, in line with the case law of the Court of Justice. It is also necessary to provide for specific provisions in case of overlapping of long-term care benefits in kind and in cash." [emphasis mine]

After Recital 24, the following is inserted:

"(24a) Long-term care benefits refer only to those benefits which have the primary purpose of addressing the care need of a person, who on account of impairment due to, for example, old age, disability or illness, requires considerable assistance from others to carry out essential activities of daily living for an extended period of time. Moreover, long-term care benefits refer only to those benefits which can be considered **as social security benefits within the meaning of the Regulation.** In line with the case law of the Court of Justice in, for example, Case C-433/13, Commission v Slovak Republic, social security benefits are those benefits granted without any individual and discretionary assessment of personal needs to beneficiaries on the basis of a legally defined position and long-term care benefits should be interpreted accordingly. **In particular, long-term care benefits do not include social or medical assistance.** Benefits granted on a discretionary basis, after an individual assessment of the claimant's personal needs, are not long-term care benefits covered by this Regulation" [emphasis mine]

Article 1 is amended as follows (...):

(d) The following point is inserted after point (va):

"(vb) 'Long-term care benefit' means a benefit in kind or in cash the purpose of which is to address the care need of a person who, **on account of impairment [in the Commission proposal the wording was different: "on account of old-age, disability, illness or impairment"]** requires considerable assistance from another person or persons to carry out essential activities of daily living for an extended period of time in order to support **his/her personal autonomy**; this includes benefits granted for the same purpose to the person providing such assistance;" [emphasis mine]

After Article 35, the following Chapter is inserted:

“CHAPTER 1a

Long-term care benefits

Article 35a

General provisions

1. Without prejudice to the specific provisions of this Chapter, Articles 17 to 32 shall apply *mutatis mutandis* to long-term care benefits.
2. The Administrative Commission shall draw up a detailed list of long-term care benefits which meet the criteria contained in Article 1 (vb) of this Regulation, specifying which are benefits in kind and which are benefits in cash.
3. By way of derogation from paragraph 1, Member States may grant long-term care benefits in cash in accordance with the other Chapters of Title III, if the benefit and the specific conditions to which the benefit is subject are listed in Annex XII and provided that the outcome of such coordination is at least as favourable for the beneficiaries as if the benefit was coordinated under this Chapter.

Article 35b

Overlapping of long-term care benefits

1. If a recipient of long-term care benefits in cash granted under the legislation of the competent Member State receives, at the same time and under this Chapter, long-term care benefits in kind from the institution of the place of residence or stay in another Member State, and an institution in the first Member State is also required to reimburse the cost of these benefits in kind under Article 35c, the general provision on prevention of overlapping of benefits laid down in Article 10 shall be applicable, with the following restriction only: the amount of the benefit in cash shall be reduced by the reimbursable amount for the benefit in kind which is claimable under Article 35c from the institution of the first Member State.
2. Two or more Member States, or their competent authorities, may agree on other or supplementary measures which shall not be less favourable for the persons concerned than the principles laid down in paragraph 1.

Article 35c

Reimbursement between institutions

1. Article 35 shall apply *mutatis mutandis* to long-term care benefits.
2. If the legislation of a Member State where the competent institution under this Chapter is situated does not provide for long-term care benefits in kind, the institution which is or would be competent in that Member State under Chapter 1 for the reimbursement of sickness benefits in kind granted in another Member State shall be deemed to be the competent one also under Chapter 1a.”.

PALLIATIVE CARE

from EU law perspective

- In September 2014, an informal meeting of the Council of European health ministers during the Italian Presidency tackled the question of pain therapy and palliative care.
- The Commission is preparing a European framework for palliative care.
- Various research projects have also been developed under the auspices of and with funding from the European Union. In 2014, a “European Declaration on Palliative Care” was launched in Brussels under the form of a petition during the Final Conference of the Impact and Euro Impact projects (please find attached).
- In 2008 the European Parliament issued a Report PALLIATIVE CARE IN THE EUROPEAN UNION [please find attached], suggesting different options:

Option 1: status quo: Trust that palliative care will develop by encouraging the use of general public health tools already in place in most countries, such as the Patients’ Bill of Rights or regulations limiting the waiting time in healthcare centres. If palliative care were officially included in healthcare services offered by the national health service, no new laws would be necessary.

Pros: This horizontal approach respects national competencies and eliminates the need to create complicated monitoring systems and tools to ensure that the rules are complied with. Usually the only possible tool is the threat of financial penalties. New legislation is also perceived to increase bureaucracy and inflexibility, and recommendations and guidelines are not sufficiently practical.

Cons: Great differences in the availability and quality of palliative care throughout Europe suggest that this approach may be ineffective. It is clear that development in many places remains patchy, uncoordinated and poorly integrated with wider systems of health and social care delivery. A “push” from the EU could stimulate national development; indeed, the *Recommendation Rec (2003) 24* has been followed by numerous national initiatives. Furthermore, failing to pass EU measures could be discouraging to patient groups and national palliative care associations who actively seek more public support.

Option 2: General recommendations (but not new legislation) promoted by the European Parliament:

Pros: any practical developments need to be based on appropriate needs assessments. This has proven to be very useful in some countries with less-developed palliative care systems, particularly in Eastern Europe, where recommendations can be used as a tool for advocacy and lobbying. This would still respect the idea expressed by some Member States’ ministries which do not see the need for any new EU legislation, although they would accept certain guidelines in the palliative care field.

Cons: this would perhaps be perceived as a too modest contribution in a field where basic equity and proper European harmonisation needs to be ensured. Potential recommendations which could be considered:

- Encourage all countries to devise national plans for palliative care and end of life care in close collaboration with professionals and representatives of patients and families and to establish at least one national centre of excellence in the field.

- Promote availability and proper use of opioids when needed (through guidelines)
- Promote integrated healthcare networks which include proper attention to palliative care
- Improve information and knowledge systems, including support for research and evaluation in the areas highlighted above, as part of the next EU Framework Programme.

Option 3: New legislation (directives) and proactively led actions promoted by the European Parliament, ensuring patient rights and access to proper palliative care:

Pros: this would be the bravest option and would certainly be useful in countries with the to develop palliative care systems. This could be complemented with all or some of the previously systematised recommendations

Cons: complexity of the legislative generation at the European level; harmonisation between countries (many of whom have palliative care plans in place) would be problematic.

Potential legislation and proactively led actions promoted by the European Parliament which could be considered :

- Act or Directive on the Status and Rights of Patients, guaranteeing equal rights of patients, and the European regulation on access to health care and minimum waiting times these already guarantee and cover the main topics of the palliative care field.
- Ensure availability of opioids when needed (through proper legislation)
- Development of an EU strategy, action plan and monitoring system.
- Creation of a dialogue with Member States to identify priorities and an action plan and consider the need for Council Recommendations, as above
- Launching of an EU Platform for palliative care to promote cross-sectoral cooperation (health, education, social services...) in line with the objectives of the proposed strategy
- Establishment of an interface between policy and research to promote the development of indicators, certification for professionals and monitoring systems and to propose priorities for palliative care
- Development of resources, materials, tools and services
- Public policies that enable palliative care to be mainstreamed
- Declaration of palliative care as a basic human right
- Creation of a European reference centre or European Institute of Palliative Care to monitor and guide research, track service development and promote evidence based policy, education and practice
- Developing a “road map” for cross-border cooperation between Member States and/or specifically support rights of patient mobility between countries