

# The family dimension of LONG-TERM CARE

Prague, 11 December 2018

Irene Bertana
Policy and Advocacy Officer
COFACE Families Europe



### **Contents**

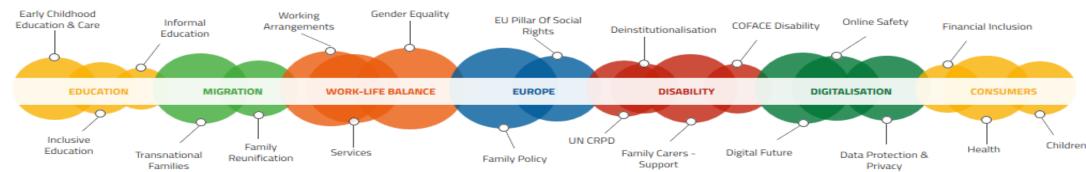
- COFACE Families Europe
- A snapshot of LTC and families in Europe
- European and International legislative framework on LTC
- COFACE initiatives on LTC
- Key recommendations to shape long-term care systems for and with families



### **COFACE FAMILIES EUROPE**



- Pluralistic organization
- Founded in 1958
- 58 organisations in 23 Member States
- "A better society for all families"
- Values: Non-discrimination, Human rights, Social inclusion,
   Gender equality, solidarity, empowerment
- Holistic life cycle approach
- Advocate for the rights and interest of all types of families
- Monitor EU initiatives, build the capacity of COFACE network





# A SNAPSHOT OF LTC & FAMILIES IN EUROPE



#### **GENDER ASPECT:**

Working carers part-time work: Women: 50% Men: 10%

For 31% of inactive women caring responsibilities are the main reason for dropping out the labour market

> **FAMILIES HAVE TO INVEST GREAT AMOUNTS OF MONEY AND TIME IN LTC**

due to the lack of social protection, affordable services and flexible working arrangements

> 1,5% GDP is the average public spending of OECD countries on LTC but it covers just a small part of the costs of LTC leaving the rest to families

#### **RECIPIENTS:**

Persons with disabilies or chronic conditions, elderly people

Increasing need with demographic change: 1 out of 3 European will be 65+ in 2080

ADLs/IADLs rehab.

**RANGE OF SERVICES:** 

transport, housing, basic medical treatment. nursing, meals. occupational therapy, household chores, meal preparation, managing money...

**LONG-TERM** CARE

#### **FINANCING:**

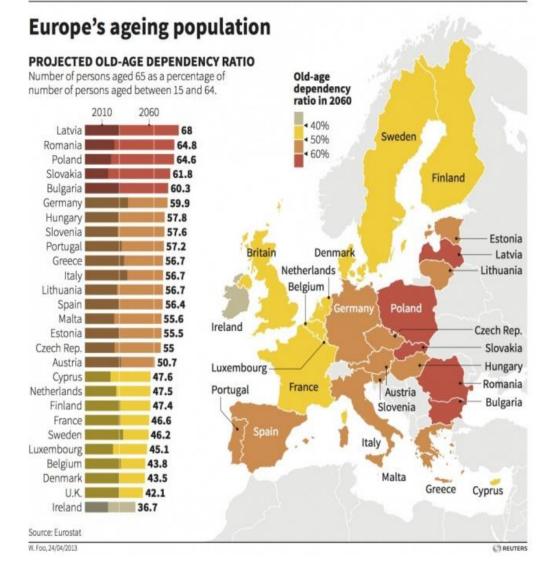
High costs Maketization of the sector Fragmentation at EU level Public financing never covers it completely

#### **SUPPLY:**

Residential Care Centres Community-based services Domestic workers (often migrants) Family members (80%)



#### **Projected old age dependency ratio by 2060**



#### **Public expenditure on LTC in the EU**

Country	Public expenditure in 2010	Projected public expenditure in 2060 – AWG Reference Scenario	Range of projected public expenditure in 2060, taking into account improved disability and policy changes
Belgium	2.3	5.0	4.7-6.2
Bulgaria	0.5	0.8	0.7-1.4
Czech Republic	0.8	1.5	1.3-2.0
Denmark	4.5	8.0	7.5-9.1
Germany	1.4	3.1	3.0-5.9
Estonia	0.5	0.8	0.7-1.3
Ireland	1.1	2.6	2.5-3.3
Greece	1.4	2.6	2.4-3.5
Spain	0.8	1.5	1.4-3.1
France	2.2	4.2	4.1-6.9
Italy	1.9	2.8	2.7-4.6
Cyprus	0.2	0.3	0.2-0.3
Latvia	0.7	1.0	0.9-4.4
Lithuania	1.2	2.3	2.1-4.7
Luxembourg	1.0	3.1	2.8-4.8
Hungary	0.8	1.4	1.3-2.0
Malta	0.7	1.5	1.3-4.3
Netherlands	3.8	7.9	7.4-9.0
Austria	1.6	2.9	2.7-4.1
Poland	0.7	1.7	1.6-2.8
Portugal	0.3	0.6	0.6-1.3
Romania	0.6	1.7	1.4-3.2
Slovenia	1.4	3.0	2.8-5.6
Slovak Republic	0.3	0.7	0.6-2.3
Finland	2.5	5.1	4.8-5.8
Sweden	3.9	6.4	6.1-7.1
United Kingdom	2.0	2.7	2.5-3.9
EU 27	1.8	3.4	3.2-5.0



# EUROPEAN AND INTERNATIONAL LEGISLATIVE FRAMEWORK

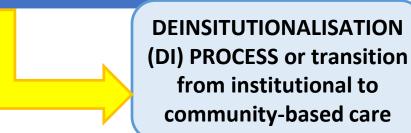


# UN Convention on the Rights of the Persons with Disabilities

## Article 19 – Living indepedently and being included in the community:

- Equal right to live in the community with choices equal to others
  - full inclusion and full participation in the community
    - Right to choose the place of residence
  - Access to in-home, residential and other community support services including personal assistance
- Availability of community services and facilities for the general popultion to persons with disabilities

RATIFIED BY THE EU AND BY ALL ITS MEMBER STATES









2010 EU2020 STRATEGY

2012

EU Year for Active Ageing

2013 Social Investment Package

SWD 'Long-Term Care in Ageing Societies-Challenges and Policy options'

2015 SUSTAINABLE DEVELOPMENT GOALS GOAL 1: social protection systems

GOAL 3: Healthy lives and well-being at all ages

**GOAL 5.4:** recognize and value unpaid care and domestic work

GOAL 8: protect labour rights for all workers including migrant workers

2017
EU PILLAR OF SOCIAL RIGHTS

PRINCIPLE 18: right to affordable, quality LTC services in the community and inhome

PRINCIPLE 9: parents and carers have the right to leave, flexible working arrangements and access to care services

NEW START INITIATIVE:

Proposal for a Directive on Work-Life balance for parents and Carers

**REPORTS** 

2104 EC – SPC Joint Report on Adequate social protection for long-term care needs in ageing society 2018 European Social Policy Network (ESPN) report Challenges in longterm care in Europe

**EU SEMESTER** 

Fiscal sustainabiliy / access to quality services

ESF + : policy reforms,
Deinstitutionalisation, acces
to quality services



Call for social innovation and social investment to close the gap between LTC needs and provision / Examples of good practices

EU2020 STRATEGY **2012**EU Year for Active Ageing

2013 Social Investment Package

SWD 'Long-Term Care in Ageing Societies-Challenges and Policy options'

**EUROPAN SEMESTER** 

Emplyoment guidelines CSRs

**Employment guidelines 2018:** MS should ensure the right to timely access to affordable health care and LTC while safeguarding the sustainability in the long run

**CRSs 2018:** AT sustainability, FI reform to improve costeffectiveness/equal access, BE cost containment, SI reform of the LTC sector

MFF 2021-2027

ESF +

**ESF proposal:** access to quality LTC, modernising social protection systems, access to social protection, support to policy reforms, support to the transition from institutional to community-based services



#### SUSTAINABLE DEVELOPMENT GOALS

GOAL 1: End poverty in its forms everywhere - Social protection systems

GOAL 3: Healthy lives and well-being at all ages

GOAL 5.4:
Recognise and value unpaid care and domestic work

GOAL 8: protect labour rights for all workers including migrant workers

#### EUROPEAN PILLAR OF SOCIAL RIGHTS

PRINCIPLE 18: right to affordable, quality LTC services in the community and in-home

PRINCIPLE 9: parents and carers have the right to leave, flexible working arrangements and access to care services

#### **NEW START INITIATIVE:**

Proposal for a Directive on Work-Life balance for parents and Carers



#### 2018 European Social Policy Network (ESPN) Report

### Challenges in long-term care in Europe

- Analysis of LTC system in **35 countries**
- Informal care expansion due to lack of accessible formal LTC facilites, that when available have poor quality and high costs
- Increasingly important role of migrant workers / lack of policy responses

#### **NEED FOR STRONGER SUPPORT TO CARERS:**

- Information, training & counselling
- Respite care
- Regular checks on availabity and willingness of family carers to fulfill their caring role
- Explore possibilities to **share care tas**ks between more than one carer
- **Improve social security** for informal carers
- Adequate LTC working arrangements / leaves to improve carers labour market participation
- Enhance LTC benefits in kind
- Pay attention to status, qualifications and working conditions of migrant workers
- Effective checks and supervision of the quality of care



# COFACE INITIATIVES ON LONG-TERM CARE



## **European Expert Group on the Transition from Institutional to community-based care**





- Support reforms that support the transition through the allocation of EU funds
- Avoid funding of institutions
- Identify good practices
- Coach policy makers at national level



#### **EUROPEAN CHARTER FOR FAMILY CARERS**





2007-2017

#### **FAMILY CARERS**

- Lack of services, social protection and financial compensation
- **Isolation and social** exclusion
- Right to choiche
- **Need for recognition**
- **Need for person-centred** flexible solutions
- Lack of good examples to follow





#### 2012

**Transnational families** overrepresented in the care sector, need for recognition of skills and diplomas

#### **2017** - ongoing



**Campaign for the WLB Directive** including (5daysyear) paid leave and flexible working conditions for carers as EU minimum standards



16 EU countries

1060 answers

85 % women aged 35-64

'Combining work with family care is very complicated. There is a rejection and a totla incomprehansion for the situation you are suffering from'

'I've lost my job because of the disability of my son'

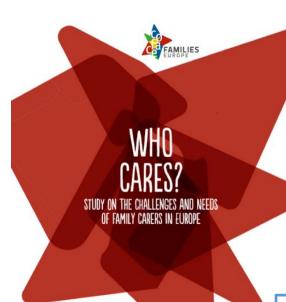
27% providing care for more than one person

1 every 3 providing care for 56+ hours/week

73% is receiving no financial compensation for their caring work

31% receiving no help in their caring tasks

1 every 3 having an hard time to make ends meet and feeling social isolation



'There's nothing for self-emplyed, your life is completely suspensed and you have no schemes or rights.'

'No job, no recognition from the State, therefore there isn't any remuneration'

'Caring for a person should be regarded as a REAL job even if it is done with LOVE'

'Policy makers must take us seriusly, without us, averything collapses'

PREFERRED FORMS OF

**SUPPORT:** in-home nursing

care, repiste, personal

assistance <sub>Se</sub>

Person-centred flexible solutions

'The conditions in which my house is, due to the fact that I cannot work and don't have money, seriously contributes to the deterioration of my health'



# KEY RECOMMENDATIONS TO SHAPE LONG-TERM CARE SYSTEMS FOR AND WITH FAMILIES



Mainstream Long-Term Care in EU policy initiatives

LONG-TERM CARE:
THE FAMILY DIMENSION
KEY RECOMMENDATIONS FROM COFACE

FAMILIES EUROPE TO SHAPE LONG-TERM CARE SYSTEMS FOR AND WITH FAMILIES

Drive policy reforms in a more integrated and holistic way solving the fragmentation between the health and social sector

Life-cycle approach

European **Recommendation** on Family and Informal carers

Tackle needs and rights of formal carers, family carers and persons with long-term care or support needs



# LONG-TERM CARE: THE FAMILY DIMENSION Y RECOMMENDATIONS FROM COFACE

KEY RECOMMENDATIONS FROM COFACE FAMILIES EUROPE TO SHAPE LONG-TERM CARE SYSTEMS FOR AND WITH FAMILIES

#### **RECOMMENDATIONS AT NATIONAL LEVEL**

- Provide access to community-based services
- 2. Right to choice
- 3. Health prevention
- 4. Legal recognition and social security
- 5. Work-life balance policies to address care penalty
- 6. Improve the working conditions of the long-term care sector
- 7. Administrative changes to improve access to informations and support
- 8. Involvement, inclusion and awareness-raising

#### **RECOMMENDATIONS AT EUROPEAN LEVEL**

- 1. Driving policy reform towards a more holistic long-term care
- 2. Adopt and consolidate legal measures to improve the social protection of family carers and of persons in need of care
- 3. Research and innovation
- 4. Legal recognition and social security
- 5. Monitoring and evaluation of national reforms
- 6. Transformative EU funding investments



### **THANKS!**

...QUESTIONS?