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European Parliament

Interest Group on
Informal Carers

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*The Concept of
Care Poverty and Its
Implications for Policy
Debate and Development*

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The need for a new approach

- Discussion on social care has focused on indicators like
 - Expenditures (% of GDP)
 - Volumes of service provision (% of age groups)
- And on concepts like
 - Marketisation
 - Familialism or De-/Re-familisation
 - Personalisation
- While these are certainly useful, they do not provide an answer to the primary (outcome) question:
 - *Do people who need help receive adequate support?*

Unmet needs

- In gerontology, the concept of *unmet (long-term care) need(s)* has been used since the 1970s
- It is a parallel concept to unmet health care need(s) that is measured, e.g. by waiting times to medical care
- Williams et al. (1997): “Unmet need occurs in long-term care when a person has disabilities for which help is needed, but is unavailable or insufficient”.
- Since the 1990s, a rapidly growing literature on unmet needs has emerged, especially in the US
- In the 2000s and 2010s, studies on unmet needs increased also in Europe (especially in the UK and Spain), Asia and even Africa

Unmet needs

- Unmet needs is often used as a pseudo-medical term (e.g., speaking about its prevalence) but lacking adequate care is not an illness, it is a social problem
- The term of unmet needs lacks a connection to discussions on inequality, deprivation, disadvantage and social exclusion – and human rights
- The term of unmet needs does not properly reflect the urgency and the seriousness of the issue

Alleged elderly murder-suicide shows flaws in Japan nursing care insurance system

介護殺人
(kaigosatsujin)
“care murder”

January 10, 2020 (Mainichi Japan)

Japanese version



The place where the 88-year-old mother was found. Flowers were found placed at the site the day following the incident, on Dec. 17, 2019. (Mainichi/Shunsuke Ichimiya)

FUKUOKA -- At the end of 2019, in this western Japan city's Nishi Ward, an elderly woman and her elderly daughter were found dead. From the circumstances, it is believed that the mother killed her daughter, who was confined to her bed, then killed herself.

[Related] Local governments adopt support policies to secure foreign labor in caregiving industry

[Related] Man who killed mother with dementia driven



WORLD | ASIA

In Graying Japan, Caregiving Concerns Drive Some Families to Murder

Parents were the most frequent victims of killings within Japanese families, a new police study found

Care poverty

- Care poverty means a situation where, as a result of both individual and structural issues, people in need of care do not receive sufficient assistance from informal or formal sources, and thus have care needs that remain uncovered.

Care poverty

- The concept of care poverty aims to build a new starting point for discussion on social care
- It connects studies on unmet needs to policy discussions on care systems and, furthermore, on poverty and social inequality
- Following the thinking of poverty research, care poverty is seen as *a lack of resources*, that is, as *a lack of informal and formal care resources*

Care poverty

- Care poverty is not a subcategory of poverty but rather its parallel concept
 - poverty is about a lack of material resources
 - care poverty is about a lack of (immaterial) care resources
- Empirical studies show that poverty and care poverty are often connected (as material resources can usually be exchanged to care resources) but these two are to be understood as separate issues

Care poverty

- Existing research on unmet needs shows that, besides low incomes, care poverty is connected to living alone, poor health and a high number of I/ADL limitations
- Several factors and social inequalities thus affect care poverty, but this does not mean that care poverty can be reduced back to them
- Whether or not people's care needs are met is *a social issue and a dimension of social inequality in its own right*

Consequences of care poverty

- Studies on unmet needs also show that care poverty has multiple negative consequences on
 - Quality of life (e.g. being unable to dress)
 - Health (e.g. heart disease)
 - Mental health (e.g. depression)
 - Cognitive function
 - Human dignity (e.g. wetting/soiling oneself)
 - Mortality
 - Use of health care
 - Use of residential care

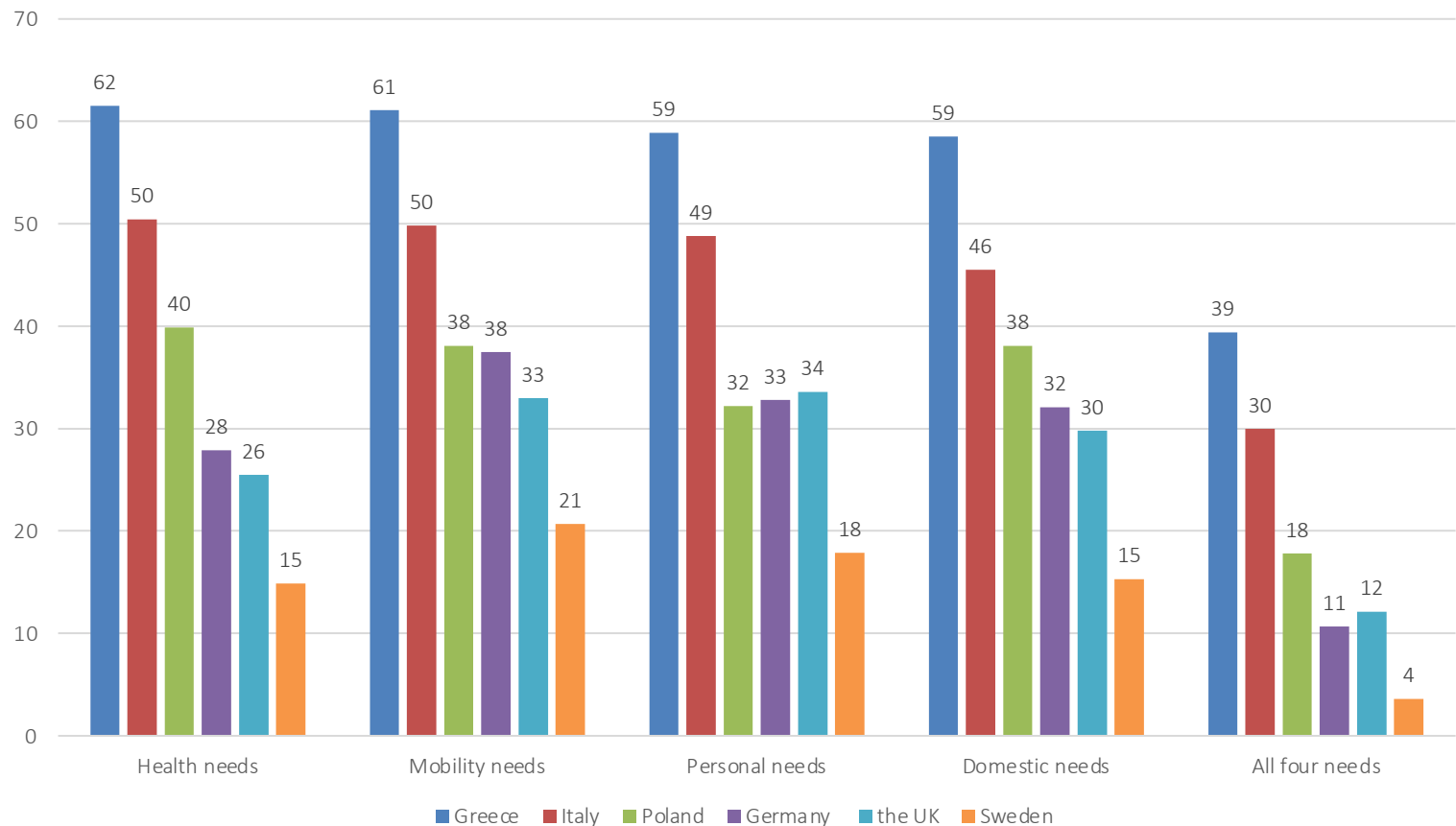
Care poverty

- The distribution of care resources among the older population in a society is a societal, political and social policy issue
- Care poverty – where it exists – can be understood as *a failure of the welfare state* (in particular, a failure of its care policies)
- It can also be seen as *a deprivation of a basic human need* and, thus, as *a human right violation*

Domains of care poverty

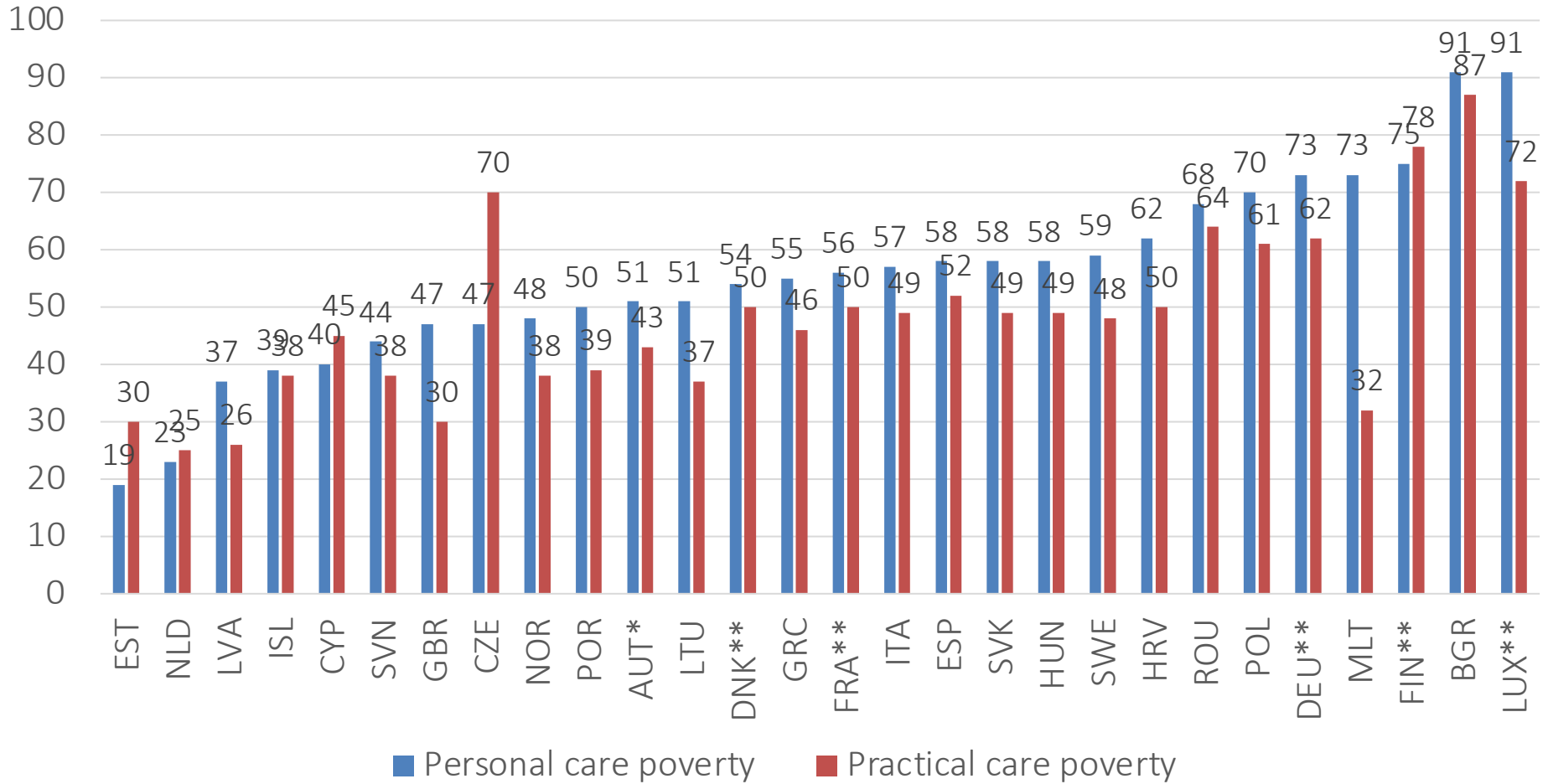
- Personal care poverty
 - Lack of support for personal care needs (ADLs)
- Practical care poverty
 - Lack of support for practical care needs (IADLs)
- Socio-emotional care poverty
 - Lack of support for social and emotional needs
 - Resulting, for example, in loneliness

Unmet needs in EUROFAMCARE data



(EUROFAMCARE project data 2003/2004)

Care poverty in EHIS data



(EHIS data 2014:

*/** Low reliability)

Care poverty and family carers

- There is less research on the consequences of care poverty for family carers – but knowledge is increasing
- Well-being and health of carers and their older family members are clearly connected
- Care poverty leads to suffering not only of the older person but also of the family carer
- Care poverty jeopardises the continuation of the informal care arrangement
- Provision of supplementary formal care supports the care arrangement and reduces the risk of care poverty

Care poverty and EU policy

- European Pillar of Social Rights 2017, 18 §
 - “Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.”
- EU Work-Life Balance Directive 2019:
the introduction of carers’ leave
 - Workers providing personal care or support to a relative entitled to 5 days of leave per year
 - Encouraging the use of European funds to improve the provision of formal care services
- European Care Strategy 2022
 - Member States asked to increase access to high-quality and affordable care services and to improve working conditions, and work-life balance for carers

Care poverty and EU policy

- EU policies are well in line with the goal of reducing care poverty
 - Developing support for family carers
 - Securing adequate formal care provisions that are affordable to all

Care poverty and EU policy

- What might still be more emphasized in policy
 - Develop collaboration between formal and informal care (to make sure no-one falls in between)
 - Put more focus on the outcomes, especially among the high-risk groups (to make sure that policies manage to meet people's needs)
 - Take care poverty as a key criterion in the evaluation of national care systems and as a benchmark in their development
 - Keep highlighting that adequate care is a basic human need and that access to it is a human right

Conclusion

- Lack of adequate care is a major risk in the rapidly ageing Europe
- Care poverty with its three domains can be understood as a critical indicator that measures the outcomes of care policies and welfare systems
- Care poverty, that is, being left without adequate care signals a major social inequality and is a violation of human rights of older people and their family carers
- The eradication of care poverty requires firm policies both at the European and the national level

Based on the Open Access book (2022)

