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**Follow-up to the World Summit for Social Development and
the twenty-fourth special session of the General Assembly:
priority theme: strategies for the eradication of poverty to
achieve sustainable development for all**

Statement submitted by the Confédération des organisations familiales de l'Union européenne, a non-governmental organization in consultative status with the Economic and Social Council*

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

* The present statement is issued without formal editing.



Statement

Making Europe's invisible workforce visible: Results of the 2017 stocktaking study on the challenges and needs of family carers in Europe.

I. Introduction

COFACE Families Europe is a pluralistic network of civil society associations representing the interests of all families without discrimination. With 58 member organisations in 23 countries, COFACE Families Europe represents more than 25 million families in Europe. It advocates at European level for policies of non-discrimination and equal opportunities between persons and between family forms, and specifically supports policies to increase equality between women and men, with a special focus on reconciliation between work, care and family life. COFACE is supported under the European Union Programme for Employment and Social Innovation (EaSI).

The COFACE Disability platform has been advocating for many years for the recognition of family carers who provide care to their relatives with support needs, through a number of rights and social benefits. COFACE Disability published the European Charter for Family Carers. According to the Charter's definition, a 'family carer is a person, woman or man, who is not a professional caregiver but by default or choice cares for a dependent person in his/her immediate circle'. The United Nations Convention on the Rights of Persons with Disabilities requires States Parties under Article 16 to take appropriate measures to prevent all forms of abuse or violence 'by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers'.

In 2017, responding to the lack of information on what family carers consider as most useful measures, or policies to better reconcile their work, care and personal life whilst respecting the choices and rights of the person they care for, the COFACE Families Europe network decided to launch a major data collection. The target group of this study is specifically family carers from different EU Member States, who are fulfilling a caring role towards a member of their family, or someone in their immediate circle. We find that the voice of family carers is often missing from policy discussions. COFACE Families Europe sees this study as an opportunity to channel the voice of family carers directly to European level policy-making and build an evidence-based advocacy strategy for the rights of family carers and persons with support needs in the future. We also see this as an essential contribution to making progress in Europe on SDG5 goal 5.4: "Recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate."

II. Main results: key emerging challenges and needs for family carers in Europe

With more than 1,000 answers collected from family carers from 16 European countries, the study provides a better understanding of the situation in Europe and offers policy recommendations from family carers to better meet their needs and tackle their social exclusion. Family carers are Europe's invisible workforce, and they represent one of the most silenced, socially excluded groups. This study takes a

closer look at who family carers are, and what are the main challenges they face, when it comes to accessing resources, services and flexible time arrangements.

One thing is clear: the current situation, in which 80% of care work in Europe falls on family carers, who are left without adequate financial compensation, social rights, or a pension scheme, is simply not sustainable.

Family carers are mostly women (85%), aged between 35 and 64, who are often part of the ‘sandwich generation’ and provide care for multiple people (27%). In our study, 1 of every 3 carers provide very high intensity care of 56 hours per week, or more, which explains that 43% of the family carers are economically inactive. There is often no one who would help them in fulfilling the caring role (31%). The testimonies given by family carers provide a comprehensive overview and also point to some core common messages:

1. Family carers face significant challenges when it comes to reconciling their professional and personal life, accessing community-based services, their financial situation, health, administrative procedures, and social recognition. It is especially concerning that 73% of the respondents do not receive any financial compensation for their work, as carers and almost $\frac{2}{3}$ of them don't have access to any kind of social benefits.
2. There are no countries in our study that would do significantly better than others in terms of providing adequate resources, high-quality support services, or flexible time arrangements to family carers to better reconcile their professional, care and personal life.
3. Being a family carer often results in isolation and social exclusion: 1 of every 3 respondents said that they are having a hard time to make ends meet, as a consequence of their caring role. In most countries, carers reported that they felt isolated with no time, or possibility to leave their house, or take part in social activities.
4. In-home support services, in-home nursing care, respite, or personal assistance are preferred forms of support service provision by family carers. Respondents mentioned that the availability of such services would relieve them from the intensive care responsibilities and would ensure that their relatives can live independently in the community while receiving high-quality support.
5. There is a great demand towards person-centred, flexible solutions: Some family carers expressed their intention to return to the labour market, whilst others would not mind staying at home, if their work as carers was recognised and financially compensated. Policy makers should take into account the choices and preferences of family carers and their relatives with care needs.

III. Conclusions: Recommendations from family carers to policy-makers

Meeting the needs of family carers contributes to the quality of care, or support and also helps to preserve a quality family life. Investment in 21st century community-based support services and family support measures, with special regard to work-life balance policies would contribute greatly to the social inclusion and wellbeing of all families.

First-hand recommendations from family carers include the following:

1. Provide access to community-based services:

Caregivers and family members of a person with support needs require support in daily activities (e.g. in-home services and personal assistants), and also need to take a break from their caring role by accessing respite care or day-care centers. It is very important that community-based services are affordable, so that the access is not only restricted to few. In this way, both carers and persons with support needs can choose the kind of support they want to give, or receive.

2. Financial support and social security:

Not being able to work or working part-time has financial consequences, which is why a form of financial contribution to the carer is indispensable. For a sustainable solution, it is furthermore very important to recognise caregivers legally, so that they are covered by social security and have access to an adequate pension.

3. Administrative changes:

When carers do not know about their rights or existing services, the uptake is very low. Thus, a central focal point, as many suggested, could be a valuable solution to provide the necessary information. Trainings and counselling should further support carers. In terms of administrative procedures, fast and simplified structures need to be put in practice, so bureaucracy will not create an additional burden.

4. Reconciliation measures:

Providing reconciliation measures is essential for employed family carers to fulfil both professional and care responsibilities. Additional days of leave, flexible working hours and the possibility to telework would improve their situation. It is important to offer flexible solutions to caregivers, since their needs and the needs of their relative may vary significantly from family to family.

5. Involvement, inclusion and awareness raising:

Respondents were rarely involved in policy making, or in the evaluation of services; Nevertheless, there was a strong request for such involvement of carers and persons with support needs. They felt that policy makers do not take them into account. Therefore, it is necessary to raise awareness of persons with disabilities and other support needs and their families to fight discrimination and isolation in society.

6. Health prevention:

Considering the impact of caregiving on family carers physical and mental health, it is crucial to apply preventive health measures. Caregivers especially demand access to psychological support, which can ease the mental stress that they are exposed to.

See full study on the COFACE website www.coface-eu.org.