Family vs. state responsibility in long-term care provision - The feasibility of one model

Marian Harkin MEP welcomed the visiting group of Irish carers and the other participants, underlining the aims of the Interest Group on Carers, i.e. to provide a forum for debate as well as initiate policy and action in the field of carers. She stated that a new way of thinking about sustainable care provision is needed, which includes the full recognition of the role and contribution of carers. Care provision is often equated with hospital and formal intramural care, while informal carers and their invaluable contribution are often forgotten ; new ways of thinking about care provision should put carers at the centre of long tem care provision systems.

Heinz Becker MEP underlined his appreciation for the personal efforts of carers and their invaluable contribution to society, as most care is in the EU is provided by carers. This resource needs to be nurtured and basic support conditions need to be put in place. While the EU cannot offer any 'hard' legislation in this field, its 'soft' power mechanisms - e.g. facilitate the exchange of experience and good practice -can be put to use. As regards the meeting's topic – state versus family responsibility – Mr Becker recalled the huge differences between the Member States in terms of vision, resources and forward- e thinking. In his own country, Austria, long term care is financed by the state and secured by law. Families receive care payments (up to 1500 euro per month) to support care needs. Not all Member States are in a position to afford this kind of support, but there could be elements in the Austrian system that could usefully be shared with other Member States.

Marian Harkin MEP then gave the floor to the key note speakers, **Diarmaid O'Sullivan** and **Paul O'Mahoney (The Carers Association, Ireland).** They emphasised that meeting the range of challenges – material and moral – posed by an ageing society has increasingly become a topic of mainstream discussion and policy initiatives in recent years. One of the most significant challenges relates to the logistical and financial burden on health and social systems. Three major issues need to be addressed : a *huge increase in need*, a threat to the *supply of long term carers as result of a variety of demographic developments and* the pressure that rapid growth in demand will place on ensuring *care quality*.

The burden of care will continue to be assumed by family members - not least because care recipients themselves express a preference for involvement of family members.

The 2014 Social Protection Committee report recommends a move from reactive to proactive models of long-term care provision and more intelligent, prudent and efficient expenditure of resources. This means that Member States must commit to support family members who are themselves committed to caring. Provision of long-term care is neither a state nor a family matter. An equitable and efficient division between family and state will require the systematic support of the former by the latter.

Eurocarers is currently working to coordinate and progress research into best practice in long-term care in Europe in order to capture important data, particularly concerning the conditions and financing of informal care (which are not being collected by EU data collected systems such as MISSOC and ESPROSS). Measures open to Member States in facing the challenges posed by long-term care needs range from reallocation or redirection of finances and refinement of healthcare institutions and services, to importation of foreign labour or taking steps to formalise black economies.

To demonstrate this, some practical examples were given:

- In **Italy**, two-thirds of care is being provided by families. There are services which are nationally coordinated, but there are regional disparities in terms of quality as well as accessibility. The use of third-country migrant workers has become especially prominent, and the regulation or formalisation of this market is a challenge for authorities.
- In **Germany** a somewhat similar situation exists, with workers from Poland and other eastern European countries coming as live-in care providers. These workers are usually working for below minimum wage and on a short-term basis. In order to address this situation, Germany has launched the so-called "Triple Win" programme, where students from non-EU and EEA "source countries" are invited to train in Germany before returning home:

  - Countries of origin gain a better-skilled health workforce
  - Germany increases the number of medical staff and improve social diversity
  - Students gain job opportunities and skills enhancement

  Partnerships under this programme currently exist with Serbia, Bosnia, the Philippines, Tunisia and Vietnam. However, there are some reservations as there could be insufficient incentive for carers to train in Germany, or for German hospitals or institutions to hire staff who must legally leave after a relatively short time.
- In **Slovenia,** responsibility for health and social care is devolved to municipalities. This is complicated as there are over 200 municipalities in a population of approximately 2 million. Inefficient administration and a greater risk of unequal access to supports and services and lack of coordination and coherence of vision are the result.
- In **The Netherlands** a new long-term care and insurance act came into force in January 2015, both of which devolve responsibility for health and social care to the municipal level. A recent study of informal carers and volunteer carers has shown that most respondents were willing to look after relatives in the future, but there was also resistance directed toward government policy which is increasingly based on informal care as the norm. The local government and insurance providers do not have enough experience in the field, and are facing difficulties in administering care. What is offered or supported also differs across municipalities.
- In **Ireland**, as opposed to most Member States, there are no statutorily or constitutionally reciprocal maintenance obligations to ascendants. This means that care of aged relatives is not legally compellable, and the responsibility for such care, if refused by relatives, falls to the state. However, due to other legal provisions, the state cannot be compelled to assume the burden of care by a court on the basis of the Constitution. The practical consequence is that families are expected (socially, though not legally obligated) to provide care and financial assistance.

It is clear that economic disparities are a barrier to coordination of long-term care initiatives across the EU. The proportion of GDP spent on health and social care varies considerably between Member States, and this remains the most significant indicator of a country's commitment to long-term care. What is also clear is that family carers will be central both to national and Europe-wide measures taken to efficiently meet long-term care challenges. As a profession, care work continues to be poorly remunerated and time-intensive. The number of live-in professional carers is likely to increase, but this scenario poses problems of regulation, both in terms of preventing abuse of clients and the exploitation of workers.

Carers will be key to successful long-term care initiatives; yet every national or multinational survey reports their feeling undervalued and inadequately supported. A single model of long-term care provision across Europe seems unfeasible. Apart from different levels of resources and regional disparities within countries there are economic and cultural differences. The speakers underlined that care is not just related to providing care for older people – it relates to the range of conditions which render a person vulnerable or disadvantaged and in need of care.

Marian Harkin MEP thanked the speakers and underlined that issues relating to carers are moving up the EU agenda for a number of reasons, not least because of the pressure by the Interest Group. It is unlikely however that there will be a harmonised system of care across the EU – and maybe that is not the most desirable option; there are different ways of providing care and the level of resources also varies enormously between countries.

The floor was then given to the first panellist, **Thomas Bignal (European Association of Service Providers for People with Disabilities).** This Association represents over 11, 000 social services for persons with disabilities and their umbrella associations from across Europe, with the objective to promote equal opportunities for people with disabilities through effective, high quality, affordable, available and adaptable social services, based on the UN Convention on the Rights of Persons with Disabilities (UN CRPD). Mr Bignal outlined the changing nature of society:

- there is a paradigm shift with regard to persons with disabilities, stimulated by the UN CRPD,
- society is ageing,
- there are cuts to expenditure in social care,
- Society is increasingly becoming a knowledge/ICT society.

As a result, support models are also changing. The social support sector has significant job creation potential due to the societal changes previously mentioned. The current focus on personal and household services (PHS) is a positive step in the transition to community-based services. However, undeclared work remains one of the largest downsides of PHS. Another issue relates to maintaining quality of services and decent working conditions.

EASPD has also developed through several projects, such as a European Care Certificate, an exam-based entry level certificate in the social care sector which translates how the principles of UN CRPD can be implemented in the day-to-day care work.

A new relation – partnership - between families and professional support providers is also required. Professionals need to have flexible approach, responding to individual's and family carers' needs; they need to become "care-brokers" to bring support closer to the needs, bring expertise if needed, and help empower families (training and retraining, respite services, etc). In order to facilitate this transition, policy-makers can put in place new funding systems which will trigger a shift in power, they can put in place self-directed support policies and help develop non-burdening accountability systems. Moreover, new quality insurance systems should be researched and developed and there should be proper support for the training and re-training of professionals and family carers. Empowerment is the key word.

The next panellist was **Paola Panzeri (COFACE),** who reminded the audience of COFACE's campaign to designate 2014 as the European Year of reconciliation of work and family life. Many organisations were involved in this campaign, and a European reconciliation package - a tool for companies and other stakeholders to put in place better practice relating to reconciliation of work and family life – was developed. How to reconcile work and care is crucial for carers, not least because of the risk of losing social security and pension rights when carers need to reduce or leave paid employment in order to care for loved ones.

COFACE recommends a clear commitment from the state to support family members. All across the EU a shift from hospital to home care can be witnessed; this shift is not sustainable if there is no support framework for carers, both financial as well as in practical terms. What needs to be avoided as well is shifting the care from a woman inside the family to a (migrant) woman outside the family; migrant care workers need a clear legal framework. COFACE would propose an EU Recommendation on family and social care, calling on Member States to recognise (the contribution of) carers and their issues.

The final panellist was **Jean-Rémy Acar (European Federation for Family Employment)** who presented the EFFE as a new player on the block, already working with all other organisations present in the meeting.

New models for the care of older and disabled people are required, taking into account the need to reconcile work and family life and facilitate the integration of women into the labour market. Long-

term care provision is a huge issue and part of the answer can be found in employing a person at home as a formal carer , also to help and support informal carers. This will of course have an impact on informal carers and on the organisation of the work between the different welfare sectors. Questions concerning social security, training and qualifications are highly relevant in this respect and these questions are valid for both formal as well as informal carers.

Policy makers have to look at ways to recognise the role of carers and define the responsibilities between the state and families. Families know what they need and will provide part of the resource required. They are active players as well as employees, at the intersection of what is at stake.

Home family employment takes into account the work/life balance and addresses both formal and informal care. This sector needs to be professionalised. It is a matter of public authorities sharing responsibility with the family, and this type of employment can make a major contribution where long term care is concerned.

Discussion

The following issues were raised:

- The home should be recognised as the central place for care provision
- Many carers work around the clock, 7 days a week. They become expert at what they do; these skills need to taken into account and recognised formally. The potential role of experienced carers needs to be recognised: they might be offered special training after their caring role has finished. This would also help them get back into the labour market.
- Families need financial as well as social support. As the need for long term care will increase, structures need to be put in place to support and facilitate carers.
- Demographic trends need to be analysed in a more meaningful and comprehensive way, taking account of the fact t that most care is provided by informal carers.
- Cuts in services means increasing the burden on carers.
- Financial planning for long term care is urgently required. One solution could be to put in place financial systems allowing families to buy in care rather than give this money to hospitals, as the financial constraints on families are huge.
- Support to carers is disjointed; the voice of carers is fragmented. A person-centred care model is required, rather than the current medical model, which ignores the person concerned. Decision makers should ask themselves what sort of care they would prefer themselves and take that as a reference.
- When cared-for persons need to go into a nursing or care home – for medical reasons or carer burn-out - the carer is left with a void and feelings of uncertainty of what might happen. While there may be a sense of relief at first, after a while depression and feelings of guilt can become apparent. There needs to be more attention to this situation.
- In Ireland, services for pre-school disabled children are in place and these are available until they are ten years of age. Sadly, from that age until the age of 30 no services exist at all, which means that care needs to be provided by families. People with disabilities in the age category 10-30 are ignored, in the community as well as in the labour marker. This needs to be addressed as a matter of urgency. All stakeholders (government, service providers NGOs...) involved should work together to change this. Support systems should be transparent and participative.
- Empowerment of carers and their cared-for seems to be the key issue. Decentralisation is happening all across Europe, and while this may be a good idea in theory, in practical terms it often means shifting of even more responsibility onto carers. As carers play a central role in care provision they need training and proper support services in order for them to continue to care.
- Lastly, it needs to be recognised that carers do not only care for older people but for people of **all** ages, regardless of their specific needs or disability.