



Review

Mapping support policies for informal carers across the European Union



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ABSTRACT

Background: At a time when health and social care services in European countries are under pressure to contain or cut costs, informal carers are relied upon as the main providers of long-term care. However, still little is known about the availability of direct and indirect support for informal carers across the European Union.

Methods: Primary data collection in all EU member states was supplemented with an extensive review of the available literature.

Results: Various forms and levels of support have been implemented across Europe to facilitate the role of informal caregivers. Financial support is the most common type of support provided, followed by respite care and training. Most countries do not have a process in place to systematically identify informal carers and to assess their needs. Policies are often at an early stage of development and the breadth of support varies significantly across the EU.

Conclusions: Policy developments are uneven across the member states, with some countries having mechanisms in place to assess the needs and support informal carers while others are only starting to take an interest in developing support services. Given the unprecedented challenges posed by population ageing, further research and better data are needed to capture and monitor information on informal carers, to help design adequate support policies and eventually to evaluate their impact across the EU.

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1. Introduction

European long-term care (LTC) systems rely heavily on provision of care by informal carers. Recent estimates show that informal carers contribute over three-quarters of all LTC provided [1,2], and the size of the informal care “workforce” is evaluated to be at least double that of the formal long-term care workforce [3]. However, future supply is uncertain for a number of reasons, including the decline of intergenerational co-residency, higher employment rates

of women, and rising old age dependency ratios [4]. Projections to 2060 show that the supply of informal care is unlikely to keep pace with the increasing demand in Europe [5]. Estimating the number of informal carers across the European Union is a difficult task, given differing definitions of caregiving [6], and the fact that the actual number of informal carers is usually higher than the number of carers receiving support under LTC programmes [2]. The latest data available show that about 6% of the population aged 50 or over provides care to an older relative in Europe [7]. Considerable cross-national variations are found, with the highest proportions of carers in Mediterranean countries and the lowest in Sweden, Switzerland and the Netherlands [7]. Informal carers are most likely to be female (spouses or adult daughters), except in the over-75 age group where

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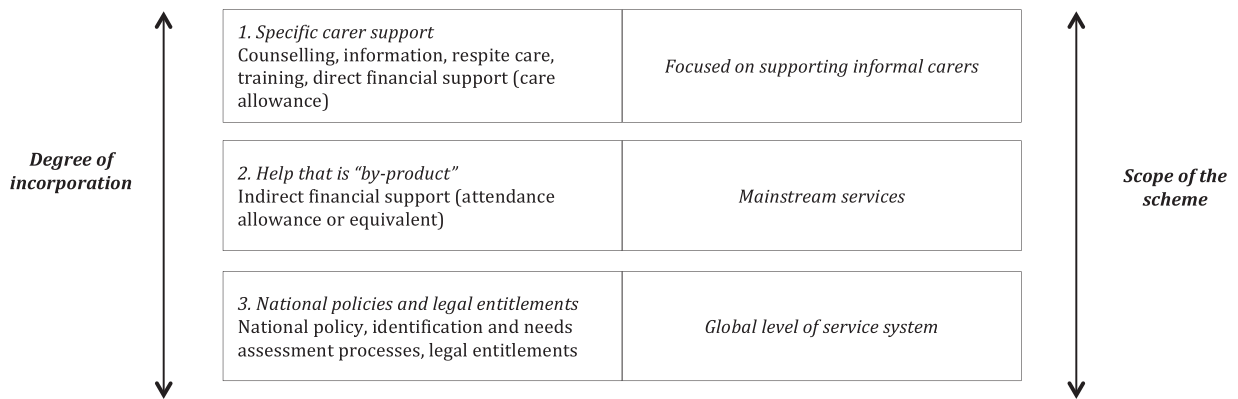


Fig. 1. Theoretical framework. Source: Adapted from Twigg and Atkin [21].

there is an equal or higher percentage of male carers in most European countries [6,8].

The European Union has acknowledged that population ageing presents unprecedented challenges to national health and social care systems and intergenerational solidarity [9]. Recent initiatives have targeted the employment opportunities and working conditions of older Europeans as well as their active participation in society beyond employment and healthy ageing [10,11]. Thus far, informal care provision and its challenges have not been a key component of the EU's response to population ageing. Despite their relevance to the future of LTC services in Europe, support services for informal carers remain largely under-researched. At national level, concerns about how best to support informal caregivers have featured on the political agenda of a number of European countries in recent years. Often considered as "by-products" of the LTC system [12], informal carers and their needs had long been ignored by policy-makers [13]. European states have gradually implemented policies to compensate for income lost due to caring, but also to facilitate caring activities [2].

However, when it comes to services designed to support informal caregivers, only limited evidence is available. Previous studies investigating support services have mostly been country-specific [e.g. 14–16]. Existing comparative research has been restricted to a small number of countries [e.g. 2,13] or has not focussed specifically on support offered to informal carers [6]. The possibility for policy-makers to learn from other countries' experiences is therefore limited. Supporting carers is a concern among EU citizens. A recent Eurobarometer survey reported preferences regarding government contributions to helping carers. Financial remuneration for caregiving was considered to be the most important support for informal carers, followed by flexible working arrangements and pension protection [17].

Against this background, we investigate the actual provision of support across the European Union. As a first step, this article aims to provide a comprehensive picture of the support available directly or indirectly for informal carers across member states. A detailed analysis of the depth of support services offered in each member states is beyond the scope of this paper but the mapping exercise will

provide an overview of the arrangements in place in a rapidly changing policy area.

The first section provides an overview of the framework and methods used to collect national information. The main results of the mapping exercise, in terms of direct and indirect support available, national policies and legal entitlements, are then set out. The discussion section highlights challenges associated with providing support services for informal carers and future directions for policy and research.

2. Materials and methods

Comparative research in the area of informal care is limited by the lack of data available, and the differing definitions, institutional arrangements and cultural expectations (e.g. whether the obligation for relatives to provide care is enshrined in national law) [13,18,19]. The definition of "informal care" used for the purpose of this article is broad, to capture all the dimensions of caring activities [20]. It covers any help provided to older family members with functional limitations (which includes activities of daily living as well as instrumental activities of daily living). What counts as services for informal carers is also complex to define. Carers are often not the direct focus of a service, but feature in the service system via their relationship with the cared-for person [21]. To determine which services to include in the mapping, we used the framework designed by Twigg and Atkin [21]. The aim of the framework is to cover all services potentially provided for informal carers, but also the broader policy environment within which these services are provided. It distinguishes between three levels of support for informal carers (see Fig. 1). The first level includes services provided in order to support directly informal carers, such as counselling, respite care or training services. The services included at the second level come to the caregiver as a "by-product of the services aimed at the cared-for person" [21]. The focus of the service or scheme is on the cared-for person but the ripple effect on the carer can be considerable, e.g. when a cash allowance can be used to pay an informal carer. The third and last dimension covers national services and practices as well as the assumptions made

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