O'Sullivan, D et al 2017 Family Carers as Partners in Implementing Integrated Care: Maximising the Impact of Ireland's National Carers Strategy. *International Journal of Integrated Care*, 17(5): A301, pp. 1-8, DOI: dx.doi.org/10.5334/ijic.3618

## CONFERENCE ABSTRACT

## Family Carers as Partners in Implementing Integrated Care: Maximising the Impact of Ireland's National Carers Strategy

17<sup>th</sup> International Conference on Integrated Care, Dublin, 08-10 May 2017

Diarmaid O'Sullivan<sup>1</sup>, Paul O'Mahoney<sup>1</sup>, Liam O'Sullivan<sup>2</sup>

1: Family Carers Ireland, Ireland;

2: Care Alliance, Ireland

Crucial to the success of integrated care networks is the role of family carers in their creation (Leichsenring K. 2004). When networks are poorly integrated, carers suffer; they are often invisible to the system, and have their needs neglected or ignored. The resulting breakdown in care at home increases pressure on formal services (Binstock et al. 1996). A dual challenge now exists EU-wide: to support informal or family carers through integration of formal services for care recipients, and to involve them in formal care systems (Leichsenring K. 2004).

The goals of Ireland's 2012 National Carers' Strategy (NCS) represented an acknowledgement of the need to integrate family and formal care. Its vision is to recognise and respect family carers as key partners, and to support them to maintain their own health and wellbeing and to care with confidence (Department of Health (IRL), 2012).

Drafted and adopted in the midst of economic recession, the NCS had limited resources for delivery on its objectives. The challenges for a cost-neutral strategy were various: how to secure buy-in of carers; how to measure progress from carers' perspectives; and how to establish and consolidate fruitful collaboration between government ministers, officials and family carers.

Health policy that impacts upon integration of care in Ireland, in particular that related to home and community care, suffers from an implementation deficit (Browne M. 2016). A major factor in that deficit is that, where policy and strategy development often proceeds via widespread engagement with stakeholders, subsequent implementation forsakes their further involvement.

The NCS sought to address and partially remedy this. Family Carers Ireland (FCI) set up an independent monitoring group composed of family carers and key experts from FCI and Care Alliance Ireland. The Group devised a simple 'traffic-light' scoring system to monitor progress in the strategy's implementation. Scores were assigned based on comparison between stated NCS goals and annual government progress reports. Assessment was further informed by the lived experience of family carers, which often served to confirm or confute elements of the reports. The scoring process took place annually, and finalised scorecards served to inform

family carers nationally and the general public, and as the basis for engagement with government ministers and officials.

The initiative's innovative aspect lies in its promotion of carers' engagement with health and social policy implementation. The approach supported family carers to monitor progress toward stated integrated care objectives, and facilitated their communication with key stakeholders. Positive engagement from government ministers and officials, and receptiveness to the expertise of an external monitoring body of family carers enabled a collaborative, solution-focused approach to implementation of the NCS.

Full achievement of the strategy's goals is still some way off; but this collaborative approach has yielded positive and tangible results. These include establishment of a cross-divisional Health Service Executive working group; marked improvements in how Government engages and communicates with family carers about available supports; extension of the period of a carer's receipt of key welfare supports after the care recipient's death or entry into residential care; and an enhanced Annual Carer Forum.

In terms of transferability, Government departments have recommended that other interest groups replicate this approach. In other jurisdictions, this approach could enhance the implementation of Integrated Care Policy that requires the active involvement of patients and carers.

## References:

1- Binstock R, Cluff L, Von Mering O. The Future of Long-term Care, Social and Policy Issues. Baltimore/London: John Hopkins University Press. 1996.

2- Browne, M. Responding to the support and care needs of our older population. Report on the forum on Long-term Care for Older People. SAGE, Support and Advocacy Service for Older People. Ireland. 2016.

3- Department of Health. The National Carers' Strategy. Department of Health. Ireland. 2012.

4- Leichsenring K. Developing integrated health and social care services for older persons in Europe. International Journal of Integrated Care. 2004.

Keywords: family care; policy implementation; measuring progress; user engagement; informal care