CONFERENCE ABSTRACT

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

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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

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