Carers as Equal Partners in Care

“Carers are meant to be equal partners. However, the reality so often is that we are given all the responsibility without the support, resources or recognition. It’s so often far from being a real partnership”1

Background
Carers were first recognised in legislation as ‘Partners in Care’ in the Community Care and Health (Scotland) Act 2002. Duties around carer involvement in service planning and care assessments were further strengthened through the The Carers (Scotland) Act 2016

In 2018 and 2019 two reviews of Health and Social Integration took place, one carried out by Audit Scotland and one by the Ministerial Strategic Group for Health and Community Care. Both noted the importance of the involvement of carers and supported people for effective health and social care integration and made recommendations or proposals for strengthening the role of carers as equal partners in care

In recent years there has been an even greater emphasis on shifting the balance of power to communities, supported people and carers. The Review of Adult Social Care included the recommendation that ‘there must be a relentless focus on involving people who use services, their families and carers in developing new approaches at both a national and local level’

The government’s plans to establish a National Care Service also reflect this move, signified by the inclusion of carers in both the Social Covenant Steering Group and more recently the Stakeholders Advisory Group.

However, despite a clear recognition from government of the need to recognise and involve carers as Equal Partners in Care, more resources and support are required to enable carers to engage with strategic planning at a local and national level. Both in nurturing involvement at a grass-roots level and fully resourcing and supporting the role of carer representatives in both existing and emerging structures, such as Integrated Joint Boards and the National Care Service.

The Experience of Carers Representatives on Integrated Joint Boards
The Carers Collaborative was established in 2016 by the Coalition of Carers to support, evaluate and improve carer representation on Integration Joint Boards (IJBs)

In 2019 it noted in its scoping report that there are still areas for improvement in relation to carer involvement in strategic planning. In particular:

1 Quote from a carer engagement event on the review of adult social care
• Recruiting and retaining new carers who are willing to undertake representative roles has become a challenge
• Not all IJBs fully compensate their carer representatives. For example, expenses are not always provided for additional meetings that carer reps attend and replacement care is not always included. Expenses policies are still not in place in all areas
• Involvement in agenda-setting has improved in some areas, but carer reps are still excluded in many others.
• The role of carer representatives has grown over time, with carers being asked to attend an increasing number of planning meetings and sub-groups. While this is welcomed, steps have not been taken to widen the pool of carer representatives and as a result the role is becoming unsustainable

Recommendations
All public bodies, including the Scottish Government, should involve carers of all ages in planning, development and delivery. Lived experience must be at the heart of developments and given equal status. This should include:

Phase 1 (COVID Recovery)
• Involvement in plans for COVID recovery and service remobilisation.

Phase 2 (Carers Strategy)
• Involvement of unpaid carers of all ages in local and national strategic planning as equal partners
• Ensuring local structures exist and are resourced to enable carers to take part in local strategic planning at a grass-roots level. For example, funding local carer organisations to facilitate local carer forums
• Ensuring that unpaid carer representatives on strategic planning groups, including IJBs, are fully recompensed and that expenses policies are in place in all areas. This should build on the best practice expenses policy produced by carer representatives on the Carers Collaborative
• The Government should give serious consideration to providing carer representatives with renumeration for what is essentially a full-time job. It is our view that they should receive a payment or fee, similar to the approach recently taken with the Social Covenant Group.
• Funding training to identify and support unpaid carers to become involved in local strategic planning, so this is not left to one or two unpaid carers in each area
• The role of carer representatives should be clarified, building on the best practice role and remit produced by the Carers Collaborative forum for carer reps on IJBs. The principle of carers being independent members, acting in the interests of local carers should be established.
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