



Participation for Change:

Carer Involvement in the Community Care and Health (Scotland) Act 2002

In September 2002, new legal rights in the form of the Community Care and Health (Scotland) Act 2002 recognised the contribution of many thousands of unpaid carers in Scotland. Carers Scotland supported carers in being closely involved in the process of developing this legislation. Carers were involved in drafting guidance, strategic planning, lobbying, consultation, giving evidence and working with Members of the Scottish Parliament. Carers Scotland sought to facilitate as much direct involvement of carers with Ministers and MSPs as possible. This briefing reports on a study of how Carers Scotland helped to ensure carers views were included in new community care legislation by the Scottish Parliament.

Key Points

- A variety of supports greatly helped carers maximise their participation in the policy process:
 - Practical support in the way of expenses, sensitivity to meeting times, respite care, and summarising complex information etc.
 - Empathetic support was also important, for example treating carers views and experience seriously, respecting their opinions; and providing training in attending professional committee meetings enabled carers to feel less intimidated and more able to participate on an equal basis.
- Carer organisations were successful in both representing the interests of their members, and supporting individual carers and local carer groups to become involved in the policy process.
- The inclusion of a wide range of national and local carer organisation and individual carers in the policy process ensured that carers got their message across to key policy actors.
- Regularly summarising and sharing information on the policy process within the carers community was highlighted as a key support for carer involvement in policy development.
- The input of carers was welcomed by Ministers, Members of the Scottish Parliament and civil servants.

"All round it was a good experience. I would like to think other carers would get more involved, because it helps, you're not just helping yourself"
(a carer)

Background

One of the stated aims of Scottish devolution was to give citizens more opportunities to influence the development of Scottish policy. The involvement of carers in the policy process leading to the Community Care and Health (Scotland) Act 2002 is highlighted as an example of citizen involvement in policy development. This project explores the role of Carers Scotland and the experiences of individual carers as they worked to ensure carers' views were included in the Community Care and Health (Scotland) Act 2002. It documents Carers Scotland's relationship with other Scottish carer organisations and their efforts to facilitate direct contact between carers, Ministers and Members of the Scottish Parliament.

The study method

Interviews were conducted with Carers Scotland staff (past and present), carer members of Carers Scotland's management committee (past and present), and representatives from four other Scottish carer organisations. All the interviews covered key events in the policy process. The interviews with Carers Scotland staff and members considered the internal workings of Carers Scotland, their efforts to promote participation by their members in the policy process, and supports that were provided for their members during those activities.

The study outcomes

Outcomes from the study identified elements that helped or hindered the involvement of carers in the development of the Community Care and Health (Scotland) Act 2002. These elements are listed below in four categories: the policy process, carer organisations, Carers Scotland and carers.

The policy process

What helped carer involvement?

- Politicians were interested in producing carers' legislation.
- The creation of the Carers Legislation Working Group to consider both legislative changes and guidance notes that would accompany the Act.
- The wide membership of the Carers Legislation Working Group, which included the main carer organisations and an individual carer.

- The productive working environment of the Carers Legislation Working Group that made all participants feel that they made a worthwhile contribution to the process.
- The willingness of Members of the Scottish Parliament, Scottish Ministers and civil servants to engage with carers.
- An individual carer was invited to give evidence to the Health and Community Care Committee of the Scottish Parliament.

"Everybody contributed key things to (the Carers Legislation Working Group), without all of us contributing to the process it would (have been) nowhere as strong"
(a carer)

What hindered carer involvement?

- The Community Care and Health (Scotland) Bill did not include all the recommendations from the Carers Legislation Working Group.
- The tight timescale for the consultation on the Community Care and Health (Scotland) Bill.
- The unclear impact of the consultation exercise on the content of the Community Care and Health (Scotland) Bill and absence of an analysis of consultation responses.

Carer organisations

What helped carer involvement?

- Local, regional and national carer organisations were already well established in Scotland and were experienced in engaging with politicians and civil servants and lobbying.
- The Coalition of Carers built links between carer organisations on the national, regional and local stages.
- Carer organisations worked cooperatively on the Carers Legislation Working Group sharing resources, skills and information freely.
- Carer organisations formed a campaign group to organise lobbying activity.
- Carer organisations sought to include their members at every stage of the policy process, from forming their policy positions to lobbying MSPs.

- Carer organisations supported local carer groups and individual carers to become involved in the policy process through the provision of expenses, respite care, training on participating in formal meetings and the regular distribution of accessible information on the policy process.
- Carer organisations recognised the opportunities presented by devolution and worked cooperatively to achieve their common goal of improving the situation for carers.
- Carer organisations embraced the diversity of the carers movement and supported the full range of carers to make their voices heard.

What hindered carer involvement?

- Lack of time and resources to engage with more carers.
- The problems of engaging with difficult to reach carers, such as young carers and those from ethnic minorities.

Carers Scotland

What helped carer involvement?

- Carer Scotland's Policy and Parliamentary Affairs Officer provided regular, accessible summaries on the progress of the Community Care and Health (Scotland) Bill through the Scottish Parliament. This information was freely distributed to carer organisations and carers.
- Supporting an individual carer to participate in the Carers Legislation Working Group and give evidence to the Scottish Parliament. This support was practical (providing travel expenses and materials) and also emotional to ensure the carer felt valued and included in the process.
- Carers Scotland is a carer-led organisation. A sub-group of the management committee was convened to ensure carers were involved in developing Carers Scotland's strategy and policy.

"I think the carer's input was crucial because it provided the day to day reality of the issues (...) having someone who lives it day in, day out is often a good illustration of why things need to happen"
(a member of staff)

What hindered carer involvement?

Carers Scotland felt the same limitations as other carer organisations in their efforts to include carers in the policy process (see before).

Carers

What helped carer involvement?

- The provision of practical support, understanding of carers' needs and recognising carers have responsible and intelligent opinions.
- The ability to choose when and to what extent individual carers became involved in the policy process.
- The provision of accessible, uncomplicated information through a variety of methods (email, internet, mailings, word of mouth), and access to people with expertise on the policy process.
- The existence of a network of national and local carers groups that allowed carers to work together and support each other.

"(Carers Scotland's Policy and Parliamentary Officer) was extremely good at being able to look at policy and say that's the important things we've got to look at, and then take the comments that people have made and make it into a very workable document"
(a carer)

CARERS Scotland

Carers Scotland is part of the parent organisation Carers UK which also has offices in Northern Ireland, England and Wales. It is a registered charity run by carers for carers. Carers Scotland provides support to anyone who is a carer, and undertakes a variety of work to support the needs of carers, including: providing information and advice to carers; lobbying government, and raising awareness among employers, health professionals, members of the media and the general public about issues that affect carers.

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What hindered carer involvement?

- The main difficulties were practical ones. It was difficult for carers to make time for lobbying activities; understanding documents and tackling the huge amounts of complex information was difficult for carers, although it was helped very much by Carers Scotland's Policy Officer.

Conclusion

The involvement of carers in the development of this policy process was a positive one. Both carers and carers' organisations had a favourable impression of the Scottish Parliament and MSPs. Many carers commented that they did not expect to be so well-received and felt that their opinions had been truly valued. The Health and Community Care Committee of the Scottish Parliament was praised by the carer

representative who felt that they treated her as having an expert opinion.

The partnership between carer organisations and individual carers worked well. The existing structure of local and national carer organisations with experience in engaging with their members and policy actors was highlighted as important. The partnership between professional voluntary workers and carers worked well. Complementary individual personalities contributed to the success of this partnership.

The Community Care and Health (Scotland) Act 2002 provides evidence that the civil servants, Members of the Scottish Parliament, Scottish Ministers, carer organisations and carers have embraced the opportunities presented by devolution to increase access to the policy process by individual citizens. Being involved in the policy process was seen as positive by all the interviewees and is an example of the benefits of an inclusive approach to legislative development.

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Other publications from this project include:

Involving people in the development of policy: examples from the experiences of carers in Scotland

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