



CARE 21: THE FUTURE OF UNPAID CARE IN SCOTLAND

Commissioned by the Scottish Executive, the report, “Care 21: The future of unpaid care in Scotland” was launched on 30 September 2005 by Lewis Macdonald, Deputy Minister for Health and Community Care. This study is the first of its kind in Europe and the report has major significance for carers in Scotland and for the future of unpaid caring.

The report reflects the views of carers, with over 5000 carers taking part in surveys and many also taking part in interviews, focus and stakeholder groups to inform the research for the report.

Twenty-two recommendations have been made within the report. These recommendations are not just aimed at the Scottish Executive but also at the UK government, NHS Scotland, local authorities and health boards, statutory and voluntary sectors and carer organisations. The report projects a bold vision for carers in Scotland – based on a strong framework of rights – where the contribution of carers to society, including the economic impact, is fully recognised and where carers are fully included in a society which will provide them with adequate support.

This briefing provides a summary of the report and key recommendations. However, if you would like to read the full report, it can be found online at www.opm.co.uk/scottishcarers/paper.htm Additional printed copies will be available at local carers centres or through the organisations listed at the end of this guide.

“Today is a significant day for carers across Scotland and for those who support them... to launch what I believe is a hugely significant report; a report that will create an agenda for even more change in the way that carers are valued and supported in our society... it offers a new vision for carers, building on existing progress. It offers the opportunity to help families across Scotland make positive choices about their lives. And it offers an opportunity to improve the life chances of those who look after our most vulnerable citizens, addressing issues of inequality that currently affect the lives of so many carers.”

Lewis Macdonald, Deputy Minister for Health & Community Care on the launch of “A future for unpaid care in Scotland”.

A vision for unpaid carers

Carers made clear that there should be a rights-based approach towards carers. The report sets out this vision, based on the Universal Declaration of Human Rights, where all individuals who care for a relative, friend or neighbour will have an established set of rights, which include:

- The right to social security and to economic, social and cultural rights.
- The right to work, to free choice of employment, to conditions, equal pay for equal work, to just and favourable conditions of work and to protection against unemployment.
- The right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.
- The right to a standard of living adequate for health and wellbeing.
- The right to training and education
- The right to participate in culture, arts and science and benefit from them.
- The right to take part in governance and to access services.

In this vision, our society will allow **carers to be people first and unpaid carers second** who can fulfil their potential as citizens. Those not already caring will view unpaid caring as a **positive life choice**, which is underpinned by the human conditions of love, empathy and devotion to fellow human beings.

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RECOMMENDATION 1:

That the Scottish Executive develop a Carers’ Rights Charter in Scotland

Young Carers

Young carers are a group with very different requirements. Their role differs from adult carers in that they should not be viewed as partners or providers of care, **but as children first who should be supported within the family setting**. The research uncovered a need to develop a national framework for young carers.

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RECOMMENDATION 2:

That a national forum representing the views of young carers be established and supported by a separate Young Carers Strategy

Shifting the Balance

The evidence suggests that there is considerable support to **shift decision-making about resource allocation** (i.e. purchasing power) toward the unpaid carer and the cared-for person. Carers requested that those they care for have more access to direct payments or individualised budgets.

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RECOMMENDATION 3:

That a range of measures to enable greater control and choice including shifting the balance of “purchasing power” be fully explored by the Scottish Executive.

Training and Information

The need for a high quality provision of information and training to unpaid carers is a common theme from the research. Carers identified the need to access **training and information on their caring role** but also to have the opportunity to access further **education and training to fulfil their own employment and personal development needs**. The research also highlighted a need for **carer awareness training** as a fundamental and essential part of health and social care training. **Carers should have an input to the design of any training.**

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RECOMMENDATION 4:

That a national “expert carer” programme is developed. This should include training for carers to develop their own caring skills, knowledge and expertise.

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RECOMMENDATION 5:

That all front-line staff with direct responsibilities for supporting carers in “first contact” agencies are properly equipped to advise unpaid carers about their rights, entitlements and available services.

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RECOMMENDATION 7:

That professional training for all health and social care staff should include a substantial component, which relates to unpaid carers as partners in care, carers' needs and the diversity of the unpaid caring experience.

Partnership and Planning

It was evident through the research that for carers of all ages and experiences more enhanced and personalised life planning is required for the caring journey. Many unpaid carers seek a shift from "traditional" assessment, associated with the gate-keeping of resources, to person-centred planning partnerships.

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RECOMMENDATION 13:

That local authorities should work with unpaid carers to develop person-centred life plans alongside the established carers' assessment process.

Benefits, Entitlements and Employment

This is a priority area for carers. If the contribution of carers to society and the economy is to be fully recognised and supported, it is vital that unpaid carers are effectively supported with adequate finance, whilst also having the opportunity to participate in working life. Carers want to see a simplified financial welfare system and have benefits advice to be broadened into financial planning.

At a national level, carers increasingly expect government to provide new revenue to increase the availability and quality of care services.

There will be a major challenge for the future is how to enable people to balance care and other responsibilities, especially work. There is an urgent need to increase awareness amongst employers and their representative bodies about the contribution made by carers.

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RECOMMENDATION 14:

That the UK Government should review carers' benefits entitlements, tax credit and pensions, with a particular focus on removing barriers to work.

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RECOMMENDATION 15:

That the UK Government should develop a national awareness campaign to ensure that employers of all sizes are made aware of both their role and their responsibilities towards carers, and the overall contribution of unpaid carers.

Services and Support

The need for more accessible, responsive support to carers and services to those they care for was an issue that was consistently voiced throughout the study. The research uncovered an urgent call for many services to be both expanded and improved. Carers placed access to breaks and outings for the people they care for as a top priority.

When planning support to carers, local partnerships must also plan for the needs of carers with specific issues or cultural requirements including black and minority ethnic carers, carers with learning disabilities, those with mental health problems and older carers. For example, in the focus groups a specific recommendation raised by black and minority ethnic carers was the need for mainstream support services that were culturally sensitive.

The role of carer organisations and the voluntary sector was universally highly praised but highlighted the importance of building the capacity of the voluntary sector and the potential benefits of carer representative organisations combining their efforts to ensure the views of carers are communicated more effectively at a national level.

The maintenance of good health and general wellbeing is also an important issue for carers. Statutory health agencies should ensure that carers' health and wellbeing remains a public health issue. The research also identified a strong need for more counselling services.

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RECOMMENDATION 10:

That service providers ensure they meet the needs of the whole caring community, taking account of carers with special needs and the specific cultural and language needs of minority ethnic groups.

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RECOMMENDATION 16:

That the Scottish Executive, local authorities and NHS should focus strongly on the health and wellbeing of carers. Carers should have increased access to counselling and emotional support services and occupational health provision that matches paid care staff. Best practice should be rolled out to form national standards and action to address carers' health needs should be prioritised in national and local public health strategies.

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RECOMMENDATION 18:

That Scotland's existing network of local carer support organisations is strengthened.

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RECOMMENDATION 19:

That national carer organisations focus on their collective role as the "voice of carers" and coordinate effectively their capacity in the planning, development and monitoring of carer policy and support services.

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RECOMMENDATION 20:

That as an urgent priority the Scottish Executive develops a national strategic framework to ensure carers are given a statutory entitlement to breaks from caring.

Resources

A common theme from the research was the requirement for **sufficient resourcing for support services for unpaid carers and those they care for**. Both the UK Government and Scottish Executive need to investigate this further. Many of the carers involved in the research commented that services had improved but equally that there was a **need for greater investment to deliver on existing promises and fulfil need**.

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RECOMMENDATION 11:

That the Scottish Executive continues to update the Carers' Strategy to incorporate the impact of demographic and social change and to plan for resourcing of future need.

Implementation and Performance

The research uncovered strong concerns from carers that although new policies may be created – such as carers' assessments and carer involvement in planning - **they may not be effectively implemented on the ground**. There was a strong sense that although many of the policies and procedures required to improve support to carers and enhance their quality of life do already exist, they are not fully implemented and the gap between policy and practice.

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RECOMMENDATION 21:

That the recommendations are incorporated into performance management systems and progress monitored by the Scottish Executive and regulatory and inspection bodies.

What you can do...

We have produced a lobbying guide for carers and carers' organisations, which suggest ways in which you can raise awareness of the report and ensure that the recommendations are supported. A petition is also available. Both the guide and petition are available from any of the organisations listed below.

Actions that you could take include:

- **Sign the petition**, which will also be available online at www.carerscotland.org
- **Write to your local MP, MSP and councillor**, enclosing this summary report and telling them what a difference it would make to you as a carer if the recommendations were implemented. You could also visit your MP or MSP in their local surgery.
- **Write to the letters page of your local newspaper** raising the importance of recommendations, highlighting what difference they would make to your life.

This briefing has been produced jointly by Carers Scotland, the Coalition of Carers in Scotland, Crossroads (Scotland) - Caring for Carers, the Princess Royal Trust for Carers and the Scottish Carers Alliance (November 2005). For further information about the report or the work of the organisations, contact:

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