



Scottish Executive response to
Care 21 Report:
The Future of Unpaid Care in Scotland

“1 in 8 are carers”

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The Future of Unpaid Care in Scotland**

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Introduction



1. The Executive welcomes the Care 21 report *The Future of Unpaid Care in Scotland* as a comprehensive study and a valuable tool for guiding our approach to supporting Scotland's carers.

2. The Executive commissioned this report in recognition of the contribution which unpaid carers make to the provision and quality of care in Scotland. Unpaid care is likely to grow in importance as people live longer and receive more care at home. The quality of support we give to family carers is therefore crucial.

3. We commissioned the study to help us consider the main factors which need to shape the development and funding of services so that we can best support the contribution of unpaid carers over the next 10 years. The Executive made a good start to its commitment to carers with the *Strategy for Carers in Scotland* (November 1999). This resulted in significant investment in services to support carers, new carer legislation and associated guidance, and a recognition of carers as key partners in the provision of care. The Care 21 Report will help us build on these achievements.

4. A big issue addressed by the report was the future role of unpaid care in delivering health and social care services in a fast-changing world. A world where:

- medical advances and life-style changes contribute to people living longer, growing older and increasingly living alone;
- we have higher expectations of the care we should receive;
- public services will need to change and develop with public expectation; and

- people's willingness or ability to accept the loss of independence, financial instability and the health risks that caring brings may decrease, for example because of long-term financial commitments.

5. The report concluded that, whilst greater personal wealth would leave many older people able to fund more of their care, increased caring pressures will be much more prevalent in socially deprived communities, where poor health continues to be an issue.

6. *The Future of Unpaid Care in Scotland* has delivered on its objectives. The wealth of evidence, a comprehensive literature review, a household survey and the involvement of over 7,000 stakeholders - including over 5,000 carers and former carers from all parts of the country - give this study valuable weight. Both the evidence base and the report's 22 recommendations are revitalising the *Strategy for Carers in Scotland*. It has created an agenda for continuing change in the way carers are valued and supported in our society.

7. At the launch of the report on 30 September 2005, Lewis Macdonald, Deputy Minister for Health and Community Care, explained that Ministers would need to consider timescales and resource implications before responding to the report. Those recommendations with significant resource implications would need to be considered in the next Spending Review. The Executive undertook to maintain the momentum of the report by responding in spring 2006 following a period of scoping of the implications of the report's recommendations.

8. This scoping exercise included an appraisal of opportunities for mainstreaming

carer support across the government's public sector work. The vision of the Care 21 report highlights the importance of recognising carers' interests across public services, not least in the way that NHSScotland and social care services respond to the future needs of patients and those with care needs.

9. The Executive's response therefore takes account of parallel policy developments such as *Delivering for Health and Changing Lives* - on the future of the NHS and social care respectively - as well as a raft of other developments in health and social care, and other relevant areas such as transport. Given the needs of parent carers and young carers, it also takes account of key policy developments in children's services such as *Getting it Right for every Child and the Additional Support for Learning Act*. A more detailed consideration of the 22 recommendations and a response to each are at the Annex to this response.

10. We are grateful to stakeholders for their input to the Executive's assessment of the implications of the report's recommendations. In the spirit of our partnership approach to policy development, we shared an interim assessment with national carer organisations and local statutory partners and received helpful comments and proposals. These have helped to inform this response and will inform future developments.

Response Overview

11. *The Future of Unpaid Care in Scotland* sets a 10 year agenda - an agenda not only for the Executive and statutory care providers but for groups and agencies in every sector and locality.

12. To ensure real outcomes for carers and early gains, we need to select early priorities without losing sight of other important objectives. Effective action also depends on maximising opportunities which arise from a range of parallel policy developments. Responding to the priorities set out by carers in the report, and in consultation with national carer organisations, the Executive has identified four early priorities:

- young carers;
- respite;
- carers health; and
- carer training.

Young Carers

13. Better support for young carers is a widely-shared concern, the subject of much media interest and of detailed Parliamentary debate. The Executive agrees with the need for a strategic focus on young carers. We propose to achieve this initially by integrating and mainstreaming young carers within current policy and service priorities for children and young people.

14. The Executive's response sets out a number of measures to achieve this through actions flowing from the Additional Support for Learning Act, from integrated children's services planning, and from the implementation of proposals in *Getting it Right for Every Child*. At the same time, joint inspections by the Social Work Inspection Agency, Her Majesty's Inspectorate of Education and the Care Commission of child protection services are now being rolled out, and a new cross-agency assessment tool for young carer services is under development.

15. All these measures are designed to improve services working with children and young people, and to improve outcomes for young people and their families. We believe that this approach will deliver better outcomes for young carers than would the development of a separate strategy at this stage. This will help to meet the principle adopted by organisations supporting young carers that young carers are children and young people first and foremost.

16. To guide the delivery of these objectives, the Executive will move quickly to establish a task group to provide advice and information when guidance is being updated or new information is being produced. This will help ensure consistency of messages, reflection of young carers' needs and concerns, and a systematic approach to local young carer

support. To assist with consideration in next year's spending review, we will also ask the task group to:

- assess existing capacity of local agencies and projects whose primary or major focus is young carer support, making recommendations on minimum requirements for sustainable local services; and
- assess the potential role and implications of a national young carer forum.

17. As part of our review in 2008 of this response as a whole, we will review the need for a separate young carers strategy. We will also explore opportunities for a national young carer event at that stage to help take stock of young carer support.

Respite/Breaks from Caring

18. The Executive acknowledges that carers have placed respite services and regular breaks from caring as a top priority for support to help them sustain the level of care they provide. We therefore accept the need for a strategic approach to respite provision for carers.

19. We will move quickly to establish a task group to assess respite provision in Scotland; update national strategic guidance for respite services and help promote local service redesign to shift the focus of local provision to preventative, personalised respite care. Whilst the work will reflect the interests of cared for people, its primary focus will be on breaks from caring for the benefit of adult carers. (Breaks for young carers will be considered by the group set up to look at young carers' issues in general.)

20. The group's work will include an assessment of information on existing models of respite provision and need. This will assist with consideration of the recommendation for additional provision in the spending review.

21. The group will review existing respite guidance and update it where necessary to set out what should be covered in local

service planning and to underpin Local Improvement Targets for respite services.

22. In relation to the report's recommendation for a statutory minimum entitlement to respite, we are concerned that this could cut across existing local authority responsibilities for providing care and support in the light of assessment of needs and a prioritisation of available resources. If, after conclusion of the work outlined above, it appears that a statutory entitlement to respite might have a useful role to play, we will reconsider the issue.

Carers Health and Carer Information Strategies

23. The Executive recognises the health impacts that caring can have. Safeguarding the health of carers (recommendation 16) will be an early priority. It requires that carers are identified early and systematically, that they receive the information and advice they require, and that they are referred to appropriate sources of support to ease the task of caring and prevent crisis or ill-health.

24. To this end we are today issuing final guidance to NHS Boards on the development of local Carer Information Strategies, to identify carers and inform them of their rights to support. We have also taken other relevant measures. New enhanced incentives for GP practices to identify a named person with responsibility for carer identification, set up carer registers, and refer carers to local support came into effect in April. And a toolkit for Community Health Partnerships to assess their management of long-term conditions - to issue later this year - will highlight the support which carers require to support patients with long-term care needs.

25. The Executive's response also highlights a carer focus in new *Prevention 2010* pilot programmes for health improvement in deprived communities; in a national Review of Nursing in the Community; and in plans for patients and carers to have access to their own electronic health records.

Carer Training

26. The Executive recognises the value of training to help carers develop the knowledge and skills to manage their vital role while minimising the impact of caring on their own health. The need for the 'expert carer' is brought out in *The Future of Unpaid Care in Scotland* but also in *Delivering for Health*. That is why we have made carer training an important element of our guidance on NHS Carer Information Strategies (recommendation 6) and have funded Carers Scotland to pilot a new carer training programme.

27. Early results from a study by the Coalition of Carers in Scotland and the Princess Royal Trust for Carers show excellent training practice in some areas. The overall picture, however, is varied and patchy. We will discuss with stakeholders the development of a national 'expert carer' training framework to help improve consistency and share best practice. We will also consider the recommendation for an expansion of carer training in next year's spending review.

Financial Implications and Review of Response

28. The Executive will not lose sight of other objectives. A more detailed response to each of the 22 recommendations is contained in the Annex to this response. In addressing early priority areas and subsequent work our approach will continue to be guided by the priorities of carers and by close partnership working with national carer organisations and local partners.

29. Many of the recommendations in *The Future of Unpaid Care in Scotland* have significant funding implications. In line with the Executive's normal approach to significant funding issues, these will need to be considered in next year's spending review. Therefore, alongside our priorities identified above, the response indicates areas where we will work to assess further the costs and benefits of certain recommendations in advance of the spending review.

30. In 2008, following the Spending Review and in light of progress with the actions identified in this response, the Executive will revisit its priorities in response to the 22 recommendations.

Conclusion

31. *The Future of Unpaid Care in Scotland* is very valuable in guiding public policy for carers in Scotland over the next 10 years. The Executive takes the report's recommendations seriously. In this initial response, we have set out how we intend to focus on initial priorities while not losing sight of wider objectives. We recognise the crucial contribution which unpaid carers make to Scottish society and the report's messages that unpaid care is likely to grow in importance. Support for carers is a crucial strand of health and social care policy and delivery. We need to maintain and strengthen that strand by continuing to work with carers and other stakeholders to take forward the actions set out in this response.

Scottish Executive
24 April 2006



Individual Recommendations – Detailed Consideration and Scottish Executive Response

RECOMMENDATION 1: We recommend that the Scottish Executive should develop a Carers’ Rights Charter in Scotland

- The charter should be consistent with the principles of the Universal Declaration of Human Rights (UDHR).
- It should fully recognise carers for their huge contribution to society in supporting relatives and friends.
- It should make specific reference to the UN Convention on the Rights of the Child (UNCRC) to ensure young carers are supported in their development as children and young people in a family setting, and not just as care givers.
- The charter should be developed by all agencies whose activities impact on the quality of life for unpaid carers and, in particular, carers’ organisations, local authority and health organisations and employers.

Scottish Executive response

1. The Executive is interested in the potential for a carers’ charter as a way of promoting the recognition of carers’ contribution to society, their status as partners in providing care and their rights. We acknowledge the recent Carers UK Report, *Whose rights are they anyway: Carers and the Human Rights Act*, as a valuable contribution to the question of a charter. While a charter will not be one of our immediate priorities, we will look at the implications before reviewing this action plan

in 2008, when the outcome of the spending review will be known and the likelihood of a European Charter should be clear.

RECOMMENDATION 2: We recommend that a national forum representing the views of young carers be established and supported by a separate Young Carers Strategy

The strategy should focus on the following areas as priorities:

- implementation of clear agency responsibilities to aid early young carer identification and support, particularly for school, education and health services
- enhanced joint working between agencies with young carers and their families
- a person-centred, life-planning focus to harness the ability of young people and their families to create appropriate support
- a need for sustainable voluntary sector organisations and networks that can offer young carers peer support, breaks from living and caring routines, and person-centred learning and development support.

Scottish Executive response

2. We agree with the need for a strategic focus on young carers. At this stage, rather than a separate young carers strategy, we believe that it would be preferable to look at young carer support within the wider strategic

context of Ministers' agenda to improve the integration and quality of services for children and young people in general.

3. The proposals in *Getting it Right for Every Child* apply to all services working with children and young people, regardless of their needs. The proposals are founded on early identification of a child in need of support, a single integrated assessment of these needs, a single electronic record and an agreed plan of action. Where multi-agency inputs are needed, a lead professional will be appointed to ensure that the agreed plan is delivered and progress monitored. We will also take powers to require agencies to work together in the best interests of the child.

4. The Executive has already taken a number of important steps to improve support for young carers. Recent measures flowing from the Additional Support for Learning Act should help to systematise inter-agency support for children who are identified as being unable to take full advantage of opportunities at school because of a range of circumstances, including circumstances at home and caring responsibilities. Our publication, *Partnership Matters*, focuses on how additional support needs can be met in further education.

5. Importantly, guidance to local children's services partnerships (local authorities, NHS Boards, police services, youth justice and voluntary sector) on integrated children's services planning already refers to the need to take account of young carers' needs. This will however be strengthened in updated guidance.

6. Joint inspections (by HMIE, SWIA, Care Commission, etc.) of child protection services are now being rolled out. These will be extended to all services for children from 2008. The inspections will review the integration and quality of services for children, including delivery of objectives and outcomes set out in the integrated children's services plans. We believe that these mechanisms hold out the prospect of delivering better outcomes for young carers than developing a separate strategy at this stage.

7. To support a systematic approach and to help improve the quality of local support, we are already working through the Social Work Inspection Agency and Her Majesty's Inspectorate of Education to develop a self-assessment tool for young carer services.

8. The Executive has already made efforts to mainstream young carers interests in guidance and information. For example, the *Safe and Well* handbook for child protection in education features a section on supporting young carers. However, we believe there will be ongoing opportunities for more to be done to mainstream young carers' interests to help us improve the way in which local agencies work to support them. In the short term, this is likely to include guidance on integrated children's service planning (as noted above), Implementation Project for the National Review of Guidance (pastoral care in schools), and guidance to underpin our forthcoming strategy for supporting young people not in education, employment or training.

9. To ensure that all these strands of work fully reflect the needs of young carers, we will establish a task group to provide advice and information when guidance is being updated or new information is being produced. This will help ensure consistency of messages, reflection of young carers' needs and concerns, and a systematic approach to local young carer support. We will move quickly to establish the group.

10. To assist with consideration in next year's spending review of the young carer forum proposal and of recommendation 18 on capacity of local carer-focused services, we will also ask the task group to:

- assess existing capacity of local agencies and projects whose primary or major focus is young carer support, making recommendations on minimum requirements for sustainable local services; and
- assess the potential role and implications of a national young carer forum.

11. As part of our review in 2008 of this response as a whole, we will review the need for a separate young carers strategy. We will also explore opportunities for a national young carer event at that stage to help take stock of young carer support.

RECOMMENDATION 3: We recommend that a range of measures to enable greater control and choice (including shifting the balance of 'purchasing power' to carers and users) be fully explored by the Scottish Executive.

This may include the further use of self-directed care through direct payments and exploration of individualised budgets for services provided or commissioned by local authorities.

Scottish Executive response

12. We support the objective of expanding choice to both carers and cared-for people, which is a significant focus of Changing Lives (January 2006). We will integrate carers' interests into the actions it identified in this area, such as service redesign, as they develop over the coming months. (See response to recommendation 20 on respite.)

13. Making funding more individualised to the service user will be a theme within the *Changing Lives* implementation plan. This includes direct payments as they are currently configured, but may further extend to individualising budgets for service users, which does not require users' direct administration of the budget and procurement of care services.

14. Uptake of direct payments for self-directed care is expanding. The Executive's priority is to focus efforts on making them more accessible to existing client groups before considering any expansion in eligibility to carers in the longer term. Increasing the flexibility, choice and control which users have over their care using direct payments is one way of supporting users' independent living. It increase users' quality of life, and in so doing can also benefit carers in their lives.

RECOMMENDATION 4: We recommend the development of a national 'expert carer' programme. This should include training for people to develop their own caring skills, knowledge and expertise

This should be developed by partner agencies and should:

- Be delivered locally.
- Contain generic and condition-specific training.
- Focus specifically on carers of people with chronic conditions, and carers likely to provide intensive and long-term care.
- Be accessible to all carers, and particularly tailored to the cultural needs of carers from BME communities and the needs of carers with communications issues.
- Draw on established and best practice.
- Be free to carers, with additional funding for alternative caring arrangements.

Scottish Executive response

15. The Executive recognises the value of training to help carers develop the knowledge and skills they need in order to manage their vital role in supporting people with care needs, while minimising the impact of caring on their own health. That is why we have made carer training an important element of our guidance on NHS Carer Information Strategies (recommendation 6) and funded Carers Scotland to pilot a new carer training programme.

16. Local NHS Carer Information Strategies will need to set out the approach to identifying carers and providing them with information, including through training.

17. Early results from the Coalition of Carers in Scotland's study of carer training provision show excellent practice in some areas. However, the overall picture is varied and patchy. We will look carefully at the final study and will discuss with stakeholders the development of a national 'expert carer'

training framework to help improve consistency and share best practice. We will consider the recommendation for an expansion of carer training in next year's spending review.

RECOMMENDATION 5: We recommend that all frontline staff with direct responsibilities for supporting the needs of carers in 'first contact' agencies (local authorities, health and voluntary organisations) are properly equipped to advise unpaid carers about their rights, entitlements and available services

Adherence to this recommendation should form an important part of the performance management of these organisations by the relevant inspection and regulatory bodies.

RECOMMENDATION 6: We recommend NHS Carer Information Strategies should be implemented as an early priority in all localities and that the requirements are extended to include local authorities

This needs to be properly resourced by the Scottish Executive and strongly performance managed by the relevant inspection and regulatory bodies.

Scottish Executive response (Recommendations 5 and 6)

18. We support proactive and targeted provision of information to carers and believe that this is best achieved by effective partnership working across the statutory and voluntary sectors. The introduction of NHS Carer Information Strategies will go a long way to achieving that. The Executive is issuing guidance to NHS Boards today, requiring them to develop NHS Carer Information Strategies by 31 October 2006. Strategies are to be developed in partnership with local authorities, carer organisations and the voluntary sector. We will monitor their implementation.

19. Where Strategies work well, carers will be identified early on in their caring role. They will then be signposted to local advice, usually voluntary sector carer centres. That way carers will be systematically made aware of

their rights as well as a range of practical support services. Local authorities are already responsible for informing carers of their right to an assessment and retain a general responsibility for providing information on local services. Because of this and the need for local authority input to Carer Information Strategies, we do not propose new legislation on local authority responsibilities in this area. The proactive and integrated approach which will underpin NHS Carer Information Strategies will help to create expert and informed carers, in line with the principles of *Delivering for Health* and *Changing Lives*.

20. We have issued a letter to NHS Boards (HDL 2006 (13) Patient Focus and Public Involvement: Independent Advice and Support Service) on 3 March 2006 requiring them to establish a service to provide independent advice and support to patients, carers, service users, their families and representatives. This service should be commissioned by NHS Boards during 2006 and be provided by a consortia of local Citizen's Advice Bureaux in each Board area. This service will provide support to individuals or their representatives who wish to make a complaint or raise a concern about NHS services; provide advice and information to individuals on a variety of issues that impact on their health and well-being in order to maintain or improve these and, as the service develops, increase the provision of advice and information related to improving the health of the whole person and which covers non-NHS specific issues, such as benefits advice. This service will provide a key source of advice and support for carers in their local areas and will build on the services already provided by local Citizens Advice Bureaux.

RECOMMENDATION 7: We recommend 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

- Individuals with direct experience of caring should be involved in delivering this.
- Education staff should also have training inputs on the issues faced by young carers.
- Specific cultural and communication needs of carers should feature in professional training.

Scottish Executive response

21. We understand the importance of carer awareness training to underpin agencies capacity to provide the information carers need and to work with carers as partners in the provision of care. That is why staff training is an important aspect of our guidance on NHS Carer Information Strategies (Recommendation 6), which is issuing today, and we look forward to seeing local strategies later in the year.

22. The *National Strategy for the Development of the Social Services Workforce in Scotland* (November 2005) acknowledges the contribution of unpaid carers alongside that of the paid workforce. It aims to ensure that the paid workforce, including social workers, is adequately trained and equipped to support unpaid carers as full partners in providing care. We will soon be launching the national Care Management Training Pack, which will include a substantial element relating to carers.

RECOMMENDATION 8: We recommend a greater role for carer representative organisations in the joint planning and development of care and other services (especially housing, leisure and transport) at a national and local level.

Scottish Executive response

23. The Executive has already taken a number of important steps to improve carer involvement in local service planning which will lead to developments on the ground over the coming months.

24. There are well established statutory requirements for engaging with carers in the development of community care plans. The legislation requires local authorities to consult with carer organisations on the plan itself. Supporting guidance makes clear that Ministers also expect carers to be engaged in local strategic decision-making, without being prescriptive about the form that engagement should take.

25. We recognise the good work that many providers already do to engage service users in shaping services. Changing Lives notes that developing truly personalised services will require a new approach, developing citizen leadership alongside professional leadership. The Executive will work with partners to develop and implement this approach, ensuring that people who use services and their carers have a strong voice in the way that they are designed and delivered.

26. Community Health Partnerships (CHPs) are being established across every NHS Board in Scotland, with the explicit role of improving health and care for local communities and reducing health inequalities. They are configured around existing local authority boundaries and are intended to operate as multi disciplinary partnerships that put users and carers at the heart of everything they do through the establishment of a Public Partnership Forum in each area. The CHP guidance and regulations, issued in 2004, requires every CHP Committee to include representatives of users and carers in local Public Partnership Forums, thereby placing them at the centre of planning and decision making of every CHP in Scotland. Advice on how best to involve local users and carers (December 2004) recognises that different areas would wish to develop involvement

mechanisms that reflect local circumstances, including geography and existing public involvement. Therefore the CHPs have been given a year to work with local users and carer groups, and the new Scottish Health Council, to agree how they will be involved.

27. Looking beyond health and social care, Scotland's new regional transport partnerships will be required to promote social inclusion and address the travel needs of older people, disabled people and their carers. Among their responsibilities for public engagement, partnerships will need to involve specific groups who experience exclusion, such as carers.

RECOMMENDATION 9: We recommend that the Scottish Executive and other policy makers integrate the issues facing unpaid carers into their policy development and planning processes

This will ensure all agencies 'future proof' the impact and implementation of policy on unpaid carers in the same way as for age, race or gender equality; or other specific issues.

Scottish Executive response

28. The Executive recognises the concerns underpinning this recommendation (and recommendation 8) that unpaid carers can be excluded from some mainstream services if their interests are not properly considered in policy development. Officials leading on carers' policy already work with colleagues from across the Executive to help embed carers' interests into wider policy making. For example:

- The Housing (Scotland) Act 2001 gives rights of succession and joint tenancy to carers who have given up their own home to live with and care for the tenant.
- Legislation on concessionary fares will allow carers to access free bus travel when travelling with a cared for person who is eligible for companion travel.

- As noted above, Scotland's new regional transport partnerships will be required to promote social inclusion, engaging with and addressing the travel needs of a number of specified groups who can experience exclusion, including carers.

29. At a more systematic level, the Executive is currently developing mechanisms for ensuring the mainstreaming of equality across the Executive in line with the Executive's Equality Strategy. Part of this process includes the development of a toolkit to enable policy makers to ensure they consider the needs of disadvantaged groups. These groups are identified in the Equality Strategy and specifically include gender, race, disability, religion and belief, sexual orientation and age, some of which are also covered by statutory obligations. These six groups are broad headings and consideration needs to be given to the diversity within each of them. Within this context the interests of unpaid carers can be included considering, for example the disproportionate numbers of female carers.

RECOMMENDATION 10: We recommend 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.

Scottish Executive response

30. We are committed to ensuring equitable access to public services for everyone by proactively addressing inequality and discrimination issues relating to age, disability, gender, sexual orientation, race, ethnicity and religion and belief. Services need to be responsive to the needs of individuals, including those with cultural, language and specific communication needs. Within our wider work on *Patient Focus and Public Involvement*, the equality strand, *Fair for All: the Wider Challenge*, aims to ensure equitable access to NHS services. Boards are currently piloting Equality Impact Assessment

across new and existing policies, to identify potential negative impacts for individuals and communities.

31. As noted under recommendation 9, the Executive is currently developing mechanisms for ensuring the interests of equality groups are properly considered in all Executive policy making. Policies to support carers have systematically highlighted the particular needs of black and minority ethnic carers. We will explore opportunities for monitoring of specific groups of carers in developments around Joint Performance Information Assessment Framework and the Performance Improvement Framework that will be delivered under Changing Lives (see recommendation 21). Local monitoring of NHS Carer Information Strategies will look at the impact on specific groups. As noted under recommendation 22, we will also consider additional research for groups of carers with specific needs.

RECOMMENDATION 11: We recommend 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.

Scottish Executive response

32. This response to the Care 21 report updates our priorities for supporting carers in our 1999 Carers Strategy. We will look at the question of updating that strategy in 2008, in the light of progress with this action plan.

RECOMMENDATION 12: We recommend that carers' organisations should have a greater role in the inspection of local services that support unpaid carers and users

Regulatory and inspection bodies should support the involvement of unpaid carers and service users as lay assessors in the inspection of local services, reflecting the principle that unpaid carers are key partners in the planning, provision, and inspection of services.

Scottish Executive response

33. The Executive recognises the value of carer and user input to regulation and inspection. This is already a significant element in a number of regimes and developing in others:

- The National Care Standards were developed with input from service users, their families and carers.
- Carers and service users are represented on the Care Commission Board. The Care Commission is providing and developing a lay assessors project, which includes service user and carer input to regulation of care services.
- Although not an inspection agency, the Mental Welfare Commission for Scotland has a role in monitoring the operation of the Mental Health (Care and Treatment) (Scotland) Act 2003 and promoting best practice in its use. The Act says that users and carers should be properly involved in decision making and should have their own support needs addressed. The Commission also has user representatives and carers as Commissioners.
- The Scottish Social Services Council (SSSC) is also required to include either a service user, past user or carer on its board. The SSSC involved users and carers were used by in the approval process for the content of the new degree courses offered by all Higher Education Institutions in Scotland. The SSSC has also appointed users and carers as 'Lay Members' to its Registration and Conduct Committees.
- The Social Work Inspection Agency (SWIA) involved a carer as an inspector in their follow-up inspection of learning disability services in Scottish Borders, as well as two service users. Carer Inspectors are currently involved in the Learning Disability inspection in Ayrshire and Arran. Within the next six months all of SWIA's performance inspections of councils will involve carers as inspectors. SWIA is working with Carers Scotland and

others on the selection, training and support for carers to be involved.

- A self-assessment guide *How Good are our Young Carer Services* is being developed jointly by the Executive, SWIA and HMle, for use by all local service partners including voluntary sector young carer organisations. The guide will emphasise the development of systematic monitoring and evaluation methodologies involving young carers and their families.

34. We will continue to bear this recommendation in mind as further opportunities arise.

RECOMMENDATION 13: We recommend that local authorities should work with unpaid carers to develop person-centred life plans alongside the established carers' assessment process

This should view the carer holistically and cover every aspect of the carer's life as requested, including financial planning. Should individuals not request a full life plan, this should not prevent them from accessing support as per existing processes.

Scottish Executive response

35. While the Executive is interested in the potential for person centred life planning, our priority is still to expand uptake of carers assessments by continuing to make them a focus of Local Improvement Targets. We welcome the Coalition of Carers in Scotland's current study of carer's assessments and will look carefully at its findings to see what lessons can be learned.

RECOMMENDATION 14: We recommend that the UK Government complete an early review on carers' benefit entitlements, tax credit and pensions with a particular focus on removing the barriers to work which are inherent in the way current financial arrangements are constructed.

Scottish Executive response

36. When the Care 21 report was published, we wrote to UK Ministers to draw the report to their attention. We have maintained contact at official level and the report is helping to inform policy thinking on these issues, particularly at a time when welfare reform is on the UK Government's agenda.

RECOMMENDATION 15: We recommend that the UK Government should develop a national awareness campaign to ensure that employers of all sizes are made more aware of both their roles and their responsibilities towards carers, and the overall contribution of unpaid carers

This should be in line with the Equal Opportunities Commission's priorities which are:

- better access to flexible working arrangements;
- better framework of employment rights for carers; and
- pensions framework that does not penalise people for the time spent caring.

A range of measures should be considered by the Government, in partnership with employer and industry representative bodies, to enhance the understanding of employers in order to enable unpaid carers to balance work and care.

Scottish Executive response

37. We welcome the measures recently proposed by the UK Government in the Work and Families Bill to help carers access flexible working arrangements to balance work and caring. We also welcome the work of Carers UK, the Equal Opportunities Commission and the European Social Fund, supported by Carers Scotland, through the ACE project to promote good practice among Scottish employers.

38. The Executive recognises the importance of enabling our own staff to balance work with caring responsibilities. We already offer a number of options to support staff, such as flexible hours, part time working, career breaks and special leave for family

emergencies. We propose to keep these support structures under review particularly in light of the new Work and Families legislation, and to consider how carers can be better supported within the Executive.

RECOMMENDATION 16: We recommend that the Scottish Executive, Local Authorities and NHS agencies along with partner agencies, focus strongly on the health and wellbeing of unpaid carers.

Professor David Kerr's Report on the future of the NHS in Scotland included the following recommendations:

- Make carers' health a public health issue.
- Implement fully NHS carer information strategies.
- Encourage carer participation and partnership involvement in planning.
- Develop and provide carer training.

Further to these recommendations, we recommend that:

- Increased access to counselling and emotional support services is made available to unpaid carers.
- Occupational health provision matches that of paid care staff.
- Roll-out of best practice to form national standards and to ensure that such standards become systematised across Scotland.
- Action to address carers' health needs should be prioritised in national and local public health strategies.

It is further recommended that the five key recommendations relating to carers' health and wellbeing from the Kerr report are considered as mutually reinforcing to those made here.

Scottish Executive response

39. The Executive recognises the health impacts that caring can have and wants to help ensure that carers are supported in their caring role and stay in good health. This requires that carers are identified early and systematically, that they receive the

information and advice they require, and are referred to appropriate sources of support to ease the task of caring and prevent crisis or ill-health.

40. Prioritisation of carers' health is in line with our commitments in *Delivering for Health* (2005) to focus on preventative care and support self care for people with long term conditions. Last year's extension of free influenza inoculations to carers was an important step, and a number of further initiatives are already underway.

41. We are today issuing guidance to NHS Boards on the development of local Carer Information Strategies, to identify carers and inform them of their rights to support.

42. We have agreed new enhanced service arrangements for 2006/07 to provide incentives for GP practices to set up carer registers; to identify a named person with responsibility for liaison with local carer services and social services to improve carer identification; and to facilitate links between carers and local support.

43. We are developing a toolkit for Community Health partnerships to assess their management of long-term conditions as an important element of *Delivering for Health's* focus on supporting self-care. The toolkit will highlight the important role carers play in supporting patients with long-term care needs, and the support they require to fulfil this role. We are also supporting the establishment of the Scottish Long Term Conditions Alliance to provide a co-ordinated voice for people with long-term conditions and their carers.

44. The new Prevention 2010 pilot programme will focus on health improvement in deprived communities by enhancing primary care services to deliver anticipatory care - identifying and targeting those at particular risk of preventable serious ill-health and offering appropriate services and follow-up. The expansion of GP carer identification and referral through the nGMS Enhanced Services proposal should link to Prevention 2010 in pilot areas.

45. The Review of Nursing in the Community aims to identify the core components of a modern community nursing service which is flexible and responsive to meet the needs of patients and communities in Scotland. It will make recommendations for the future delivery of care. We recognise that it is important to work in partnership with carers on this.

46. The plans for eHealth outlined in *Delivering for Health* include patients and carers having access to their own electronic health record. This not only allows accuracy and detail of the record to be checked but could also offer a facility for the patient or carer to themselves contribute to the record. A related eHealth initiative will be to provide more online information to patients and carers to help improve knowledge and self-care. To support our policy that carers are seen as 'partners in the delivery of care', we will ensure that the new electronic patient health records include information about carers so that health professionals are aware of their role.

RECOMMENDATION 17: We recommend that issues facing unpaid carers are given proper consideration when new technology is applied to caring situations.

Scottish Executive response

47. Many aspects of the Executive's activity are relevant to the use of technology in community care, and some are involved in the provision of funding to support this, for example through Supported Living.

48. The need to ensure technology plays a part in service re-design was made in *Changing Lives*. The Equipped for Inclusion Advisory Group is advising Ministers on how to implement the recommendations of the Strategy Forum: Equipment and Adaptations. These include a recommendation to consider how best to capture the potential of technology and create an integrated portfolio of products and services equipment,

adaptations and technology. The group includes representatives from the statutory and voluntary sectors to reflect the perspectives of users, carers and service providers in its work.

RECOMMENDATION 18: We recommend that Scotland's existing network of local carer support organisations is strengthened

The Scottish Executive and local and health authorities should consider increasing the capacity of these local voluntary sector partners to deliver a range of local support to include:

- carer training and peer support;
- emotional support and counselling;
- breaks from caring; and
- carer advocacy.

We recommend that the management and leadership capacity be strengthened within these organisations with inclusion of relevant staff on national leadership and management programmes.

Scottish Executive response

49. The Executive acknowledges the important role of voluntary sector carer centres in delivering effective local carer support, and in supporting health and social care services to deliver national objectives. We will review capacity with the help of Princess Royal Trust Scotland and the Coalition of Carers in Scotland to inform consideration of this recommendation in the 2007 Spending Review.

RECOMMENDATION 19: We recommend 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.

The Scottish Executive should also continue to facilitate regular dialogue between government and ministers, and national carer organisations to develop all aspects of Scotland’s carers strategy.

Scottish Executive response

50. We welcome the national carers’ organisations positive response to this recommendation and will continue to work with them to support Scotland’s carers.

RECOMMENDATION 20: We recommend that as an urgent priority the Scottish Executive develops a national strategic framework with service providers to ensure unpaid carers are given a statutory entitlement to appropriate short breaks and breaks from caring.

- The breaks should include opportunities for breaks with or without the ‘cared for’ person.
- The national strategic framework should be supported by guidance and properly resourced at the local level to enable commissioners and providers of respite care to develop capacity for all care groups.
- The national framework should enable access to flexible person-centred short break arrangements.

Scottish Executive response

51. The Executive accepts the need for a strategic approach to respite provision for carers. We have provided significant additional resources for respite in recent years and are focusing performance management on this area through Local Improvement Targets.

52. We will move quickly to establish a task group to assess respite provision in Scotland; update national strategic guidance for respite services and help develop local service redesign to shift the focus of local provision to preventative, personalised respite care. Whilst the work will reflect the interests of cared for people, its primary focus will be on breaks from caring for the benefit of adult carers. Work on service re-design and establishing better local and national information on respite services will require a significant input from both carers and users. (Separate strategic work on young carers will address respite for this group.)

53. The group’s work will include an assessment of information on existing models of respite provision and need, to inform consideration of the recommendation for additional provision in the spending review.

54. Shifts towards early intervention and preventative, personalised care are important aspects of *Changing Lives* and the forthcoming *Changing Lives* implementation plan will flag up the importance of respite to those agendas. We will also ask the group to assist in informing the development of service redesign approaches and projects to help shift the focus of local provision to personalised, preventative respite care.

55. The group will review existing respite guidance and update it where necessary to set out what should be covered in local service planning and to underpin Local Improvement Targets for respite services.

56. In relation to the report’s recommendation for a statutory minimum entitlement to respite, we are concerned that this could cut across existing local authority responsibilities for providing care and support in the light of assessment of needs and a prioritisation of available resources. If, after conclusion of the work outlined above, it appears that a statutory entitlement to respite might have a useful role to play, we will reconsider the issue.

RECOMMENDATION 21: We recommend that the report's recommendations are incorporated into providers' performance management systems and progress monitored by the Scottish Executive and, where appropriate, relevant regulatory and inspection bodies

Particular attention should be drawn to the number of carer assessments completed by local authorities and health providers with an expectation that such assessments should be supported by person-centred planning and become more widely available.

Scottish Executive response

57. The Executive has already put in place a range of measures that will monitor improvements in support for carers. We have mainstreamed carers' issues in our four national outcomes for community care, and in the joint performance reporting system (JPIAF). This gathers information on the level of assessments, waiting times for services, and on Local Improvement Targets (LITs) for carers' services, including respite provision. LITs are designed to be challenging, address under-achievement in key service areas and promote sustained improvement. Audit Scotland also has a performance indicator for respite. These steps are good news for carers. As local partnerships' information systems develop we should be able to capture more detail, particularly through single shared assessment datasets, and we will work with the statutory and voluntary sectors to achieve that.

58. Through the introduction of NHS Carer Information Strategies, we will have for the first time key indicators on NHS support for carers. These will be developed in partnership with carers and local authorities. We will monitor the implementation of NHS Carer Information Strategies and will require annual updates from NHS Boards.

59. We have a range of qualitative indicators for carers, but need to develop a qualitative component to performance monitoring. This is starting to be addressed through JPIAF. Changing Lives seeks to develop a Performance Information Framework for social care. Consideration is already underway in the Executive on rationalising the range of performance information linking JPIAF with the proposed new Framework.

RECOMMENDATION 22: We recommend that good policy must continue to be based on good research including reliable statistical evidence with attention to the diverse experiences of unpaid carers

- This includes a further development of the Scottish Household Survey to provide more detailed information on prevalence, intensity and trends of caring. This will assist in the long-term future planning of care provision in Scotland.
- Active engagement with European networks on unpaid carers should also be established to increase the research base on unpaid carers.
- Further research on the issues facing younger carers, carers from minority ethnic communities, lesbian and gay carers, high intensity carers, older carers, and carers for individuals with addictions.
- This also includes the requirement for local authorities to collate aggregated information from individual assessments on unmet need for use in planning services.

Scottish Executive response

60. We acknowledge the importance of good statistical information and research into the needs of carers. *The Future of Unpaid Care in Scotland* is the most comprehensive piece of research undertaken in the UK on carers' issues. We already have sources of information that will provide long-term data on caring, with carer questions in the Scottish Household Survey and the census and are seeking to build on those. We will shortly be publishing a report which looks in depth at the information already available on carers in the Scottish Household Survey. We accept the need to gather more data on specific groups of carers, for example young carers, and we will consider this further and in the light of other research priorities. It is also important that we understand better the outcomes achieved for carers and this is addressed elsewhere in the response. The Executive is happy to support where possible research proposed and conducted by universities, voluntary and research organisations, particularly where it addresses Executive priorities.

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