



# The Future of Unpaid Care in Scotland

HEADLINE REPORT AND RECOMMENDATIONS

“1 in 8 are carers”

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# Introduction



This report projects a bold new vision for unpaid carers in Scotland – a vision based on a strong framework of rights, in line with the Universal Declaration of Human Rights. In this vision, the caring contribution of carers to society will be fully recognised, the economic impact of their contribution accepted, and as such they will be wholly included in a society which will provide adequate support to carers.

Carers will have rights to flexible employment practices; adequate financial support and planning; accessible information and technology; practical support; regular breaks from caring; adequate housing; training and health care; good transport links; accessible leisure and recreational opportunities.

Our society will allow carers to be people first and unpaid carers second who can fulfil their potential as citizens. Unpaid carers will be afforded the opportunity to choose when, how, and if they care. And 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.

## Purpose

This report sets out the recommendations of a research project on the future of unpaid carers in Scotland, commissioned by Care 21, a social care innovation unit within the Social Work Services Policy Division of the Scottish Executive. This work was

undertaken by the Office for Public Management (OPM) between October 2004 and August 2005.

OPM was commissioned to undertake this exercise with the purpose of pulling together thinking on how the situation for unpaid carers can be improved in Scotland, and to make recommendations to the Scottish Executive and other agencies on how this can be achieved. The recommendations in this report arise from several work streams described in more detail in Section 1 of the report. Evidence for each of the recommendations can be found in reports in the appendices which accompany this report, and which provide detailed results of each of the work streams. Each of the work streams generated findings of its own, and the recommendations in this report emerge from a synthesis of those findings.

The research process has uncovered an impetus for change for unpaid carers in Scotland and a call to reinvigorate the carers' agenda. We have discovered progressive policy direction for unpaid carers but also uncovered some gaps between existing policy and practice. Therefore, in addition to making new recommendations on the future of unpaid carers, the report includes recommendations which may already be familiar to many. Such recommendations have been strengthened by the robustness of research processes involved in this exercise, and the comprehensiveness of consultation undertaken.

# This report projects a bold vision for unpaid carers in Scotland - a vision based on strong framework of rights.

## Summary

Overall, the research has made a number of significant gains in taking forward a consideration of the future role of and outcomes for unpaid carers.<sup>1</sup> It is the first time that unpaid care has been the specific focus of a 'futures' research project in the UK. It has also created a comprehensive picture of the caring experience in a Scottish specific context which underpins the report's vision with the aspirations and consensus which exist on the targeting of public resources.

It is anticipated that the recommendations within this report will consolidate existing thinking on support for unpaid carers, whilst also creating new solutions for the future.

One overriding and consistent message emerged: unpaid carers are the largest group of care providers and as such, the largest component of the Scottish care 'workforce', making an enormous contribution to society, however this is valued.

Unpaid carers are generally optimistic about the future of unpaid caring over the next decade. However, one of the key findings from the national carers' survey suggests that the longer a person has been an unpaid carer, the more pessimistic he or she is about the future of unpaid care in Scotland.

Just over half of all respondents to the national survey felt that the Scottish Executive does not understand the role of unpaid carers 'well at all'.<sup>2</sup> Respondents were more pessimistic still about the Westminster government's understanding of the unpaid caring situation.

The most important actions cited by unpaid carers are those that would improve their quality of life, and these form important recommendations in this report:

- giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options
- increasing the benefits of people with support needs
- offering cash payments rather than services so that unpaid carers can arrange care according to needs and preferences
- a greater emphasis on information and training, advocacy, and guidance, including emotional support.

To achieve the aspirations of carers and the recommendations in this report, it is suggested that this be best supported by the principles of:

- **Greater recognition of and respect for unpaid carers as key partners and providers**

<sup>1</sup> There are a number of outputs from the research which should continue to serve as a resource for stakeholders (carers' organisations, local authorities, health agencies, the Scottish Executive, Westminster government, and other interested parties) to utilise beyond the scope of the research project. These include all the data sets (quantitative and qualitative), a 'tool kit' for conducting focus groups with unpaid carers, an economic modelling tool designed to look 10 years ahead and with the functionality to replace the core data sets on which it is based, and to put an economic value on unpaid care, questionnaires and other survey instruments which can be utilised at later dates, and a review of research incorporating comparative international case studies.

<sup>2</sup> See Appendix 3: 'Voices of Carers': Report of a National Survey of Unpaid Carers.

- **The development of a rights based policy framework to support unpaid carers.**

This means that any person with caring responsibility should have the right to the same opportunities as others, including the right to refuse to care, to choose an appropriate level of caring (i.e. to maintain a work-life balance), and for any intensity of caring to receive appropriate support from those agencies that are properly resourced to do so. This rights approach further develops the principle of recognition and respect for unpaid carers. It also validates choice, and brings unpaid caring into line with the rights based approach promoted, and largely accepted by government for people with a disability, children, women, minority ethnic groups and employees, but without elevating the needs of unpaid carers beyond any other group. Also, it embraces the huge diversity of unpaid caring situations within a rights framework that is applicable to all, whether they care now or in the future.

The research concludes that if the recommendations within the report are implemented the future for unpaid carers in Scotland will be a positive one.

## Resources

Many of the recommendations detailed in the report relate to change in practice or culture. However, some of the recommendations cannot be considered as 'cost neutral' and will have associated resource implications. It is not the purpose of this report to cost recommendations but to highlight to the Scottish Executive where additional resource may be required.

## Reserved matters

Most of the recommendations in the report refer to issues that can be progressed by a devolved government in Scotland. However, some recommendations, such as benefits

issues, relate to reserved matters that can only be progressed at a UK government level. It is the intention of the report to outline such recommendations, after which it is anticipated that the Scottish Executive will consider how to convey such recommendations to UK ministers.

## Terminology

For the purposes of this report, the term 'unpaid carer' is used to describe individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system e.g. carers allowance. This terminology is currently widely accepted by carers' organisations and differentiates unpaid carers from those who receive a regular wage for the caring task.

The legal definition of a carer is someone who provides substantial amounts of care on a regular basis for either an adult or a child, where that adult or child receives, or is eligible to receive, support services under the Social Work (Scotland) Act 1968 or the Children (Scotland) Act 1995. Family members caring for children in a range of circumstances will not come under the legal definition of a carer unless the child in question has a disability or is affected by disability.

## Structure of the report

This report is presented in four sections with two annexes:

- **Section one** is a summary of the research methodology. As noted above, this report is supported by five separate appendices. The detailed methodology for each of the research strands is set out in the relevant appendix.
- **Section two** presents key principles, themes and recommendations for the future of unpaid care in Scotland. The recommendations are presented under thematic headings, illustrated by quotes

selected as representative of the issues presented here, taken from the 'voices of carers' report of focus groups and individual interviews with unpaid carers across Scotland.<sup>3</sup>

- **Section three** presents areas where additional research may be required.
- **Section four** is a summary of all recommendations in the report.
- There are two annexes. Annex One is a summary of the development of policy

relating to unpaid carers in Scotland to date, while Annex Two is a list of appendices which accompany this report.

We hope that this report will reinvigorate future carer policy in Scotland and beyond and help to clarify thinking and sharpen action. This report and the accompanying appendices do not contain the future but, used well, might help others to create one which improves the quality of life for unpaid carers whilst also maximising their contribution.

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<sup>3</sup> See Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.



# 1

## Section One



### Summary of the research methodology

The project combined a number of research methods in order to complete a comprehensive picture of the issues faced by unpaid carers, thereby creating a robust evidence base from which solutions to existing problems and emerging trends can be created. These include:

- Review of existing research, incorporating a literature review and international case studies.
- National household survey of 2,000 members of the general public about perceptions of the caring role and their expectations about their future caring role and responsibilities.
- 'Voices of Carers' - a national, postal and web-based survey of over 4,000 carers, and a series of targeted focus groups and individual interviews with carers.
- 'Delphi' survey - a survey of a panel of over 1,000 senior managers, policy makers and representatives from carers agencies about the future context in which caring will take place, and likely 'forces and drivers' (political, social, technological etc).
- Economic Modelling Tool - the development of an economic modelling tool based on future projections of the Scottish population, and the likelihood of people being in caring roles (numbers of carers) to 2014.<sup>4</sup>
- A Stakeholder Steering Group, which has overseen progress, received interim results and acted as a panel of experts to generate recommendations, promoting the project through various networks, and acting as a critical friend. The group comprises leading academics, representatives from community and voluntary organisations, statutory organisations, and carer representatives. The Group formed the core participants for the stakeholder event.
- Project website - as a communication tool (for posting interim findings, reports and notes of meetings) and incorporating an online survey for carers and former carers, young carers, and people working in community and voluntary and/or statutory organisations.
- Future Scenarios - an important output of the exercise is to produce a number of scenarios or plausible futures. At a large stakeholder event on the 26 August 2005, the scenarios were utilised as planning tools to identify and develop 'robust actions', or recommendations that are consensus based and thought to hold for multiple possible and plausible futures.

<sup>4</sup> The strand of the work was developed in partnership with Experian Business Strategies, a specialist economic research and consultancy organisation.

# 2

## Section Two



### The vision for unpaid carers, key principles and recommendations

This section presents the vision, key principles and recommendations for the future of unpaid care that emerged from the research. The first section below outlines the Vision for carers, the second two cross-cutting principles for unpaid carers, and the third identifies a number of key themes and specific recommendations on how we can achieve the vision for unpaid carers in Scotland.

#### Vision statement

There was a common call amongst carers, reiterated later in this report, that there needs to be a rights based approach toward carers, drawing on the existing Human Rights framework to which UK government is a signatory. The following vision statement articulates this rights-based vision for carers.

Based on the Universal Declaration of Human Rights, 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 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 well-being.
- 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

The caring contribution of carers to society will be fully recognised, the economic impact of their contribution accepted, and as such they will be wholly included in a society which will provide: flexible employment practices; adequate financial support and planning; accessible information and technology; practical support; regular breaks from caring; adequate housing; training and health care; good transport links; accessible leisure and recreational opportunities.

This society will allow carers to be people first and unpaid carers second who can fulfil their potential as citizens. Unpaid carers will be afforded the opportunity to choose when, how, and if they care. And 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.

The vision above corroborates that which was produced by the Final Extended Stakeholder Steering Group at a futures scenario event on the 26 August 2005. An important part of the proceedings of this

event was for participants to validate (and critique) an emerging vision for unpaid carers. This vision reflected the findings of the other research strands, but also reiterated existing policy statements. Significantly, a strong consensus emerged amongst participants to enshrine equality of opportunity within the principles of a vision for carers. It was felt necessary to have a strong and clear statement that caring should not prevent the unpaid carer from having the opportunity to live their life. Participants felt that caring needs to be thought of as an equalities issue and so the vision should start to adopt more of the language of rights. The understanding of rights in the vision should also include the idea that the individual has the right to choose not to undertake caring duties and that the cared for person has the right to refuse caring assistance from individuals with whom they feel uncomfortable. A full account of the stakeholder event can be found in Appendix one.

## Cross-cutting principles

### 1. Greater recognition and respect for unpaid carers as key partners and providers of care

The core principle which underlines all of this report's key messages is that there should be:

***'Recognition and respect for unpaid carers as key partners and providers in the planning, design and delivery of care.'***

*This principle includes the need to:*

- Recognise that families and unpaid carers constitute Scotland's largest care force
- Harness the contribution of unpaid carers for future care provision
- Make caring a more positive life-choice
- Strengthen independent living and self-care, and improve quality of life and the quality of care

Carers should be fully recognised for their huge contribution to society in supporting friends and relatives. This has already been enshrined in policy with the inclusion of this statement within legislation; however, this research has uncovered a gap in some areas between policy and practice. It has become evident that unpaid carers are not consistently integrated in service planning and are not always supported in the delivery of care for those they care for; a view that is clearly supported through our research. For example, in the Voices of Carers survey of over 4,000 carers, 36% identified 'ensuring statutory agencies and the voluntary sector work better together with carers as full partners', as important to improving their lives. One of the key messages that will be difficult for policy makers and managers of services to hear is the degree to which many carers, through this research, reported a perceived gap between what is promised and what is delivered.

It has not been the purpose of this exercise to research the reasons for the perceived gap in detail across all localities in Scotland; however, two general themes have emerged. First, there is a concerted call from carers for a cultural change in the planning and delivery of services to recognise their contribution; and secondly there is a call from professionals and carers that increased resources are essential to improve the lives of unpaid carers.

Unpaid carers make an invaluable and essential contribution to the wider economy and to society at large. Moreover, with demographic changes, the need for informal care will increase over the coming decades. Therefore the contribution of carers needs to be recognised and valued.

*'My mother in law is going to be older. She is going to need more care and if there are no services in place then we are going to end up being ground to the ground by having to be there 24 hours caring.'* (Woman caring for her mother-in-law, Glasgow)

Without proper recognition of their contribution and appropriate support, our research indicated that the experience of many carers is that caring can be a potentially highly stressful, demanding, socially excluding experience, which often causes financial strain, and prevents people from achieving a fulfilling life outwith the caring task. However, this research has also given many carers the opportunity to express how positive an experience unpaid caring can be, a rich and diverse expression of loving family and community bonds. Many unpaid carers' calls for better services are expressed as a need for resources to assist them to undertake what they see as their 'natural' responsibilities and obligations.

The number of people in Scotland who describe themselves as carers is substantial. In 2002 a statistical profile found that there are approximately 668,200 carers in Scotland, representing 12% of the population. Of this number, the amount of time devoted by carers to their caring role can vary enormously, with different implications for the level of support or services they may require. According to recent research, 63.4% of carers (305,610 people) care for up to 19 hours a week, with 12.5% of carers (60,293 people) caring for 20-49 hours per week, while as much as 24.0% of carers (115,627 people) care for over 50 hours per week. However, the level of caring may in fact be greater than this for some carers, as our Voices of Carers survey found that 63% of 4,260 carers who responded spend over 50 hours per week caring, a significantly higher proportion than found through previous research.

Our research indicated that few of those carers who spend a significant amount of their time caring wish to become 'professionalised' in the sense by becoming 'professionals' regulated by standards and contractual obligations. However, unpaid carers do desire a greater degree of recognition for the role they play. In addition to a function fulfilled out of a sense of love or duty, for many caring has a similar impact

to that of a job. Recognition is therefore required to ensure that the 'occupational' nature of the role is acknowledged and support provided to ensure a balance is maintained between caring and other aspects of the carer's life.

The research has highlighted that carers should be enabled to 'step out' of their caring role and enjoy the benefits and quality of life enjoyed by non carers, having an ordinary life. This is perhaps best described as '*supporting unpaid carers to be all the things they are and wish to be*'.

*'I've given up my whole life. I want to be recognised. The authorities should recognise me. When I go to the hairdresser they ask me is this your day off? When I say no, I care for my son, I am made to feel lazy, like I am not able to work. The public needs to be educated as well.'* (Carer, Edinburgh)

## **2. The development of a rights based approach to services for unpaid carers**

There is strong support amongst carers for the adoption of a 'rights based' approach to carers by Government and public service providers. In the qualitative research with carers, in the review of literature, and at our futures scenarios event, the need to enshrine 'carers' rights' into policy was consistently raised. The view is that any person with a caring responsibility should have the right to the same opportunities as others. This includes the right to refuse to care, to choose an appropriate level of caring (i.e. to maintain a work-life balance), and the right to play an equal role in society and the economy.

*'As we move towards a human rights agenda, it is time to consider a rights based approach for carers.'* (Carer's representative, Edinburgh)

*'The thing I have a concern about is that I believe they are getting to a point where they are silly and over the top. At times this impacts on the disabled person's human rights - to be clean and be what*

*they want to be. Nobody is bothered about the carer's health and safety. Carers are putting themselves physically at risk. The reality is if social work says they can't do something because of health and safety and the nursing staff can't do it and it still needs to be done. Who does it? The informal carer - there you go.'* (Carer, Fife)

This is in line with the vision statement as described at the beginning of the chapter and echoes articles within the UDHR. It promotes the concept that unpaid carers are 'people first' and should be enabled to have access to similar opportunities to those who do not care.

Our research indicated that there are four main areas in which unpaid carers requested change to improve their quality of life. These include:<sup>5</sup>

- giving unpaid carers a right to regular breaks from caring and providing more and better quality respite options
- increasing the welfare benefits of people with support needs
- offering the option of cash payments rather than services so that unpaid carers can arrange care according to their needs and preferences
- greater emphasis on advocacy, information, and guidance including emotional support.

A 'Carers' Rights Charter' would address these wishes implicitly and go some way in creating an environment in which unpaid carers can have a life apart from caring.

## Key themes and specific recommendations

In order to achieve a positive future for unpaid carers based on the initial vision statement, this research has been able to

group a number of recommendations into specific themes for unpaid carers. We outline a vision for each theme and then detail the recommendations we suggest are required to achieve it. These are grouped under the following headings: recognition and status; information and training; partnership and planning; benefits, entitlements and employment; services and support; resourcing; and implementation and performance. We also make some reference to whom these recommendations are directed as many have implications for a variety of sectors and agencies.

### Recognition and status

The vision:

- The role and contribution of all carers is recognised, with their rights to equal treatment enshrined in policy and in the way services are delivered
- The needs of carers are recognised, regardless of age, gender, ethnicity, disability or sexuality
- Young carers are supported in their development as children and young persons in a family setting

In our research, we have been able to survey and interview several thousand carers. This work has given us a strong insight into the challenges faced by carers in many parts of Scotland. The key issue for many carers, which underpins many of the other challenges highlighted in this report, is the lack of recognition and status given to unpaid caring in general.

Research participants reported how they often feel isolated from, and ignored by, the wider community. They point to examples of being discriminated at work and through the welfare benefits system. They also raised many examples of how they have found it difficult to access education and leisure opportunities.

<sup>5</sup> These findings are taken from the national survey of carers, together with key messages from focus groups and in depth individual interviews and are not presented in order of importance. A ranking of which measures unpaid carers consider to have most impact is presented in Appendices 3 and 4.

Many of the specific recommendations presented throughout this report seek to alleviate some of the social, physical and financial challenges faced by carers. However, it is also important to acknowledge that a cultural and behavioural shift is required in Scotland to emphasise the important role carers play in society and that for many, this can be a positive life choice.

### Positive promotion

There has been much emphasis on the promotion of paid caring as a positive career choice and the national 'Care in Scotland' campaign has been successful in recruiting carers in a professional capacity. However, this research has revealed that the unpaid caring task is often viewed in a negative way and the impact of unpaid caring on people's lives is believed to be detrimental to their overall quality of life. A large majority of respondents to the household survey described in their own words what they thought unpaid caring involved, and its impact, many stating that it would be *'very hard and trying and very, very difficult'*.

*'Well I'd say it would be impossible to have a full life other than that if you were a carer, it would occupy a lot of your time, and you wouldn't be able to have a job, you would be there a large proportion of the time.'* (Respondent to Household Survey)

However in the course of the exercise many carers have been able to highlight the positive sides to caring. Informants in the interviews and focus groups spoke of how central caring is to the loving relationships between partners, siblings and friends and that caring can be a highly rewarding role.

In order to change the negative perception of caring it is important that unpaid caring is promoted positively at a national level with a recognition that necessary supports will be put in place to enhance the quality of life of carers.

Measures to highlight the role and rights of unpaid carers such as Carers' Rights Days have a use in informing carers of their rights and decreasing their sense of isolation, but also have a wider purpose of increasing public awareness and recognition of the contribution they play in society.

A group of unpaid carers with very different requirements from those of other carers are young carers. There is no appetite to positively promote the role of young caring but the research has uncovered a need to develop a national framework for young carers, which will address the isolation and lack of support experienced by many. The focus groups with young carers were able to uncover a range of specific challenges facing children, including the perceived lack of effective interagency working to support their needs, the lack of tailored and relevant services such as breaks, and the general lack of a national consensus and focus on their specific needs. When these issues were taken back to the Stakeholder Steering Group, and the participants at the scenario event, the need to develop a national framework specifically addressing the needs of young carers was strongly proposed. The role of young carers differs from that of 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. A national framework should acknowledge this principle and address the complexities of partnership working to ensure appropriate support is provided.

### Purchasing power

The evidence from this research suggests there is considerable support to shift decision making about resource allocation (i.e. purchasing power) toward the unpaid carer and the cared for person. Many unpaid carers reported feeling a sense of powerlessness in the face of professionals who they often feel do not properly understand their issues, and who apply eligibility criteria and gate keep resources.<sup>6</sup>

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<sup>6</sup> See especially See Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

Many professionals highlighted their unease in the role as gatekeeper as they struggle to manage resources within tight budgets. The research revealed that there is a recognition by all that resources are not infinite but the predominant request by unpaid carers is that they and the cared for person have more information and choice about the support available to them and they have greater control over the solutions created to address their support needs. Consequently, many of the recommendations in this report reflect the principle that the unpaid carer and cared for person need to have a much greater say in decision making.

*'I'm the carer yet I have no decision making power.'* (Carer with mental health problems, Glasgow)

Throughout the survey, carers have requested that those they care for have more access to direct payments or individualised budgets to allow for more flexible provision of services. This request has been furthered by some carers who have requested that such direct payments be used for the provision of their care.

**Recommendation 1: We recommend that the Scottish Executive 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.

**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.

**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.

## Training and information

The vision:

By 2014

- Carers will be able to access training as and when required to support their caring task and help them develop their own skills, knowledge and expertise
- Training for professionals will contain carer modules and input from carers and service users
- Training will be available to volunteers who are offering carers support
- Carers will be able to access training and education which will enable them to attain their own personal learning objectives and a return to employment if desired

The need for a high quality provision of information and training to unpaid carers is a common theme which emerged out of all of the strands of our research. This takes the form of:

1. Access to information about issues and available support relating to the cared for person
2. Access to information about issues and available support relating to the unpaid carer
3. Access to training to support the carer in the delivery of their care
4. Access to higher and further education and training for the unpaid carer to fulfil their employment and personal development needs.

This research has revealed that some work has already taken place in the provision of information to carers as a result of the Scottish Executive's Providing Better Information to Carers strategy. This was

highlighted as an area of development which many felt had improved in recent years.<sup>7</sup> Equally, the research into good practice in Scotland has also highlighted a number of good training packages to carers, provided particularly by the voluntary sector. However, much work is required to ensure that this is maintained and easily accessible to all.

### Information

One of the greatest resources identified by unpaid carers through this research is timely, accurate information about where to go for support and how to access that support.<sup>8</sup> In both the Voices of Carers interviews with carers and the large-scale Voices of Carers survey of over 4,000 carers, the issue of better information provision was consistently raised. Seventeen percent of all the respondents to the survey highlighted the need for better provision of information to carers as the most important change that was required to improve the lives of carers. This research highlighted the need to re-invigorate and properly resource the implementation of carer information strategies. When asked how the information deficit could be reduced, participants in both the focus groups, and the scenario event identified the need for regular (annual) national information campaigns, co-ordinated at local level with the support of carer organisations, for a range of carer groups including new carers, current carers, and former carers.

*'Information can be pretty scant to be honest. You discover things as you go along. People don't tell you what is available.'* (Carer, Wester Ross).

Relying on information campaigns alone will be insufficient to address the many concerns of carers relating to access to information.

<sup>7</sup> The research also invited examples of good practice in relation to any aspect of supporting unpaid carers to be submitted. These were collated and re-submitted to the Nuffield Centre for Community Care in Glasgow as a contribution to the national good practice database held there.

<sup>8</sup> See particularly ranking of measures thought to impact on improving the situation of unpaid carers in Appendix 3: 'Voices of Carers': Report of National Survey of Unpaid Carers and key findings of Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.



## Access to information

Access to information by carers about local services and how to access these appears to be missing on a widespread basis. According to many carers what is required is a website, phone line, or information pack which can be used by carers to effectively 'signpost' them to the most appropriate service provider.

*'It is difficult to get information as a carer - lots of services provide advice for the needs of the caree, but often see the carer as an "add-on". When the caree is ill, carers get tired, frustrated, ill and angry - sometimes services get focused in the wrong direction.'* (Carer with mental health problems, Glasgow)

*'It would be a great help if there was a carers' pack containing all information useful to carers, such as charitable organisations, local authority departments, etc. These could be made up by local authorities and distributed to all surgeries in their area.'* (Carer responding to survey)

It was felt by many carers that professionals working in local public services need to be better resourced to be able to provide information to carers. Front line staff, with direct responsibilities for supporting carers, in key 'first contact' agencies (local authorities, health and voluntary organisations) in particular need to be aware of, and be able to communicate effectively the rights, entitlements and support available to unpaid carers. Professionals have a key role to effectively 'signpost' unpaid carers to other resources if they are not eligible to receive services from their organisation. This principle applies equally to community and voluntary sector organisations but most carers raised this issue in relation to access to direct provision by statutory agencies. Information for carers should be provided in as many formats and languages as possible. It is particularly important, given the explicit concerns that

BME carers have raised about the language barriers they face, that information is presented in community languages, and bilingual workers are made available to support carers' information needs.

## Planning and performance information

In undertaking this research, we found a poor infrastructure and data pool from which to draw basic information about the number of carers, carer assessments undertaken, and satisfaction with these, at a local level.<sup>9</sup> This information is invaluable in good strategic planning practice.

### 'Expert carer'

This research has highlighted the benefits of placing greater emphasis on the development of interventions that help individuals, couples, and families develop their own skills, knowledge and expertise in areas that have been traditionally viewed as the domain of 'professionals'.

There are a number of actions that are likely to help carers both become more skilled in their own right, and be able to network with other carers and professionals to pass these skills to others. These include:

- The development and delivery of training that aims to build up the self confidence of carers to undertake a carer's role
- The delivery of training that brings together care professionals and carers to create a two-way process of learning
- Ensuring that new information systems, including databases or carers information packs, provide practical examples of providing effective care to carers

Many carers expressed the desire to be taken more seriously by professionals as being knowledgeable about the needs of the cared for person, while simultaneously expressing a willingness to work in partnership with professionals about how these needs are best met.

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<sup>9</sup> ibid.

*'Nobody told me about the state of his condition, what I would need and how I would cope. I certainly was not sure how to get him in and out of chairs, the bath and so on. We accumulated various pieces of equipment through trial and error.'* (Carer, Wester Ross)

## Training

There also needs to be a stronger focus on providing high quality 'tailored' training opportunities to carers. A common theme that emerged out of the research was that, even where training was made available to carers, it does not necessarily take into account their very different needs.<sup>10</sup>

Advocacy training also emerged as a requirement, as a means to enabling carers to work confidently alongside their professional colleagues. Those carers who were directly involved in public service decision making, or who were part of a local representative forum, felt they often did not have the appropriate training to help them communicate their own needs, and the needs of others.

*'We have a lot of carers coming to us and telling us they do not understand the language and jargon being used at local partnership meetings. Many do not feel that they can speak up. I think they need support in order to be able to contribute fully.'* (Carer's representative, Edinburgh)

## Professional awareness

The ability of carers to work in partnership with statutory and independent organisations can often be hindered by a lack of understanding in these organisations of the distinct needs of carers. The participants in the focus groups, for example, spoke regularly of their frustration at either not having their needs understood or being able to communicate their needs. Moreover, these same participants felt that in some organisations, particularly

education, training is required to ensure that staff understand how to recognise and address the needs of young carers. It is clear, therefore, that this research highlights a need for carer awareness training as a fundamental and essential part of health and social care staff training. The agencies responsible for professional training and continuing professional development (i.e. sector skills councils, local authorities, health) should target carer awareness training at a broader range of staff (especially housing staff, leisure, lifelong learning, and planning teams). It was also suggested by participants in the focus groups that carers should have input into the design of any training module. This is reinforced by our research into good practice. If effectively delivered, carer awareness training can dramatically increase the knowledge and capacity of organisations to respond to carers needs and to enable carers to make an equal contribution to influencing the services they receive. This training, as a matter of priority, should include provisions to ensure that information from carers is treated confidentially, a point that was raised by participants in focus groups.

Using carer expertise in this way can turn ignorance into competence. One key action thought most likely to support this includes the development of national 'expert carers' programmes. Such training programmes are thought likely to achieve the long term objectives of partnership and the recognition of carers as key providers of care whilst also increasing the quality of care provision to those who need it.

## 'Induction' training

The development and deployment of a core unpaid carers induction training programme is related to a national 'expert carers' programme as a recommendation for improving information and understanding about the needs of carers. The focus group

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<sup>10</sup> *ibid.*

research, and the review of literature and good practice, highlighted the need for at least the following to be included in the content of any induction training:

- Minimum basic rights and entitlements
- Practical skills (e.g. lifting and handling, condition specific content), the implications of undertaking the caring role (e.g. how it might affect benefits)
- Personal strategies for coping with the role (e.g. stress and time management)
- Managing transitions (e.g. hospital discharge, changes in key worker staff).

In addition, it was felt necessary, particularly by BME carers who took part in focus groups, that professionals and those working with carers, are inducted in a basic understanding of their different and specific cultural needs.

Consideration could be given to developing this as a programme accredited to a university or credible training provider so that the content is consistent across all delivery agencies.

*'I have been looking after my husband for 11 years and not once has anybody shown me how to use a hoist. That is a real problem. Nobody shows carers how to transfer properly. Any individual coming out of hospital, their situation deteriorating, somebody should come in and ask what do you feel comfortable with and not. And the bits you feel comfortable with, do you know how? But they don't.'* (Carer, Fife)

One action thought likely to support this concept would be for local authorities, NHS and carer organisations to collectively map and review their current training provision at a local level to ensure that training is available and targeted correctly when most required by carers. Training for carers is particularly important at the onset of the caring role and at other transitions such as returning to work post-caring, but it will be dependent on individual need. In addition, it

is important for organisations that represent black and minority ethnic communities to assess training provision to see if it is appropriate to the distinct needs of this group.

*'Nobody told me about the state of his condition, what I would need and how I would cope. I certainly was not sure how to get him in and out of chairs, the bath and so on. We accumulated various pieces of equipment through trial and error.'* (Carer, Wester Ross)

**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.

**Recommendation 5: We recommend that all front-line 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.

**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.

## Partnership and planning

The vision:

- By 2014, unpaid carers will be recognised as key partners in the planning, design and delivery of care in all caring situations
- By 2014, unpaid carers will be better integrated in joint planning of care and service developments, and in local and national partnerships
- Care agencies will plan, promote and deliver services for the whole community, taking account of the specific needs of minority ethnic groups, removing in particular cultural, language and other institutional barriers to access
- Carer organisations, including an organisation for young carers, and advocacy services will be resourced to support carers in planning individual services and broader service development and improvement

It has become evident throughout the course of the exercise that for carers of all ages and experiences more enhanced and personalised life planning is required for the caring journey. Such person-centred planning should focus on planning for 'critical junctions' in that journey which may vary greatly in different caring and family situations.

## Carers' assessments

This research suggests that unpaid carers acknowledge the need and value of professionals but are often critical of their experience of professionals as assessors and gatekeepers to services.<sup>11</sup>

At the individual level, in accordance with the principle of carers as partners and providers of care, many unpaid carers seek a shift from 'traditional' assessment (associated with the gate keeping of

<sup>11</sup> ibid.

resources) to 'person-centred' planning partnerships (providing the cared for and carer with more control over the services developed and delivered to them)<sup>12</sup>. Such assessments should take a holistic approach and consider financial, educational, employment, housing, spiritual, cultural and leisure needs as well as health and care issues.

*'Carer assessments - you fill them out and send them to social work. Nothing happens. They are sitting in a file somewhere in no man's land. I know, I've filled one out; no response. I filled out a large number for other people. I can count on one hand the number of carers that had a response. It is definitely not the be all and end all. They are sitting in one place and are not even being acknowledged. My concern is that social work departments say, we do our carers assessment, like a little box ticked. It is meaningless unless something comes from it or it is at least acknowledged by someone coming out and going over the issues with the carer. It is actually very tokenistic. If someone fills out an assessment you have at least a certain expectation that something will happen.'*  
(Carer and carer support worker, Fife)

An enhanced person-centred plan does not diminish the role of the professional, but is recommended as a tool to increase the recognition of carers as 'people first', and possibly redress the perceived power differential highlighted by many in several strands of this research. It also further shifts emphasis of support from crisis intervention to better management of critical stages in caring.

## Corporate planning responsibility

It has become evident throughout this research that unpaid carers are often perceived as the sole responsibility of health and social care agencies.<sup>13</sup> In reality, however, input is required from several other sectors including housing, education (especially for young carers), leisure and environment, and transport to help improve the quality of life for carers. In the focus groups, for example, participants were able to provide many examples of how local services, such as education, did not always consider the needs of carers. The 'carers' agenda should therefore not be the preserve of health and social care agencies and a more corporate approach should be taken to 'carers' issues - possibly within the Community Planning process.

## Young carers

It is important that the needs of young carers are articulated at a higher planning level in addition to the assessment of need at an individual level. A holistic approach to family assessment is required to ensure that the young carer's needs are recognised within the context of the whole family. The national 'Voices of Carers' survey found that young carers were less likely than other carers to have their needs formally assessed, an issue that was supported by young carers in the focus groups who also highlighted the lack of involvement of their family in assessments. Therefore, in order to support this planning process, local agencies are required to develop and agree clear agency responsibilities to aid early young carer identification and support, particularly for schools, education and health services.

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<sup>12</sup> See particularly Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

<sup>13</sup> The distribution of the Delphi survey revealed that many agencies were minded to forward the survey to their local social care or health agency, as carers were considered outside the scope of their responsibilities. The research team took care to emphasise that while this may be true where specific statutory requirements are concerned, we were interested in the views of all agencies which impact upon the future of unpaid carers.

## Services responding to the needs of different groups of carers

Equally, local partnerships need to 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. In the focus groups, for example, BME carers highlighted the need for mainstream support services which were culturally sensitive. A specific recommendation raised by BME participants in the focus groups was that services should employ more bilingual workers to provide the necessary support to BME communities, either in their own homes or in community-based establishments.

*'Being a young carer, but from a minority ethnic community, puts a different slant on it again because there are already issues of isolation but on top of that. Take my sister, she's 14 and has started to go to a young carers group and stuff, but my dad has issues around who she is going to interact with, what the group is like, if it's a mixed group. He's OK to a certain extent, you know, some things are OK and others are not appropriate. She's at an age when, you know, she's a teenager, and young adult. Who are these people she is spending time with on a more social basis, rather than at school? I mean these are implications for all parents but putting a cultural aspect on it.'* (Asian woman sharing the care of her father with her 14 year old sister, Edinburgh)

## Research to support long term planning

There was strong support from carers and professionals for policy makers and professionals to continue to plan for the

long-term needs of carers.<sup>14</sup> It is necessary therefore that the government should make more regular use of research methodologies which support a longer term planning focus (i.e. looking 10 years ahead) for issues relating to unpaid care.

**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**

**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 issues.

**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**

**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**

<sup>14</sup> See Appendix 1: Report of Scenario Planning Event 26 August 2005 - note of proceedings.

**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.

**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.

## Benefits, entitlements and employment

The vision:

By 2014

- Carers will have full entitlement to benefits and occupational conditions in line with being in paid employment
- Employers of all sizes will demonstrate a far greater understanding of the roles and responsibilities of unpaid carers and their contribution to the economic well being of the country
- Carers will be supported in their work-care balance, and training will be provided should they choose to return to work

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 through the existing benefits, tax credits and pension systems, whilst also having the opportunity to participate in working life.

At an **individual level**, carers want to see a simplified financial welfare system.

According to a large percentage of the respondents to the Voice of Carers survey, the current welfare and benefits system is over-bureaucratic and complex. Carers (current and former) also request benefits advice to be broadened into 'financial planning' which better enables people with caring responsibilities to make sound financial decisions, and potential carers to take positive steps in planning the financial impact of care.<sup>15</sup>

*'I feel that governments generally don't realise just how much money is saved by having people cared for at home. At the end of the day people are left in a situation that financially is very difficult. Instead of having a career with a proper pension, they spent years looking after a family member. Although they don't begrudge it, at the end of the day they are worse off.'* (Elderly carer, Inverness)

## Financial review

The research has identified widespread concern amongst carers about how they are currently treated through the tax and benefit system. Through interviews and the carers survey, clear concerns were raised about the tax and benefit system. These included specific criticisms about the complexities of the system, how the benefits system prevented some carers returning to work, and how benefits were insufficient to support the financial impact of caring. Forty percent of respondents to the Voices of Carers Survey felt it was important to increase the level of carers benefits in order

<sup>15</sup> See particularly Appendix 3: 'Voices of Carers': Report of National Survey of Unpaid Carers and key findings of Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

to improve their lives. A significant number of respondents also claimed that current benefit procedures were over complicated. More worryingly, there was widespread criticism about the carer's allowance which was seen as insufficient, difficult to access and inappropriately means-tested.

Carers were also concerned about the level of financial support received from the start of the caring period until benefit entitlements can be accessed.

*'Do you know the form filling you have to do and the repetition? I used to go and sit at the DSS in the queues. Most of the time I came back, because I couldn't leave him and he was frightened. It was sitting in the DSS. I couldn't believe it. If somebody was able to tell me in our circumstances somebody could come to the house. You can get it, but no one ever told me. It was only when I got the disability allowance and went to social services they said someone could come out. You have to repeat the same thing over and over again. It is such a long haul. The tax office was good. They said they could send somebody out'* (Carer whose husband suffered a stroke, Inverness)

### Financial advice and planning

The research indicated that some carers are capital rich and income poor, many require debt management advice and many balance caring income and work income. Often carers are involved in managing multiple, interdependent income streams for themselves and those they care for, and therefore longer term financial planning is an essential ingredient to any support package. This is especially the case where benefits are means-tested and therefore subject to more frequent changes as a direct result of fluctuations in income and/or the caring relationship.

*'I've done this all my life. I feel it is my responsibility, but I am not allowed to better myself. This is not classed as a job as far as Inland Revenue is concerned. Rent rebates are rubbish. I am only entitled to a Carers' Allowance for one person. Companies who come in and provide home care get paid for what they do. It costs me £25 per week just in petrol.'* (Carer who cares for mother and brother in different locations, Fife)

### National level

At a **national level**, the exercise indicated that carers increasingly expect government to create new revenue streams to underpin a growth of care services and quality.

In the course of the research, the Stakeholder Steering group considered the ways in which carers were supported in five other countries.<sup>16</sup> The purpose of this exercise was to engender a wider debate about funding, state responsibilities, and to assess the desirability and transferability of key features of each system to a Scottish context. No single model was considered preferable for Scotland, however a number of areas for further consideration were identified. These included ideas such as more formal contractual arrangements between carer, service providers and care recipient, individualised budgets as a form of direct payments, and enhanced training opportunities for volunteers and unpaid carers. This exercise confirmed an existing request that had emanated from many of the other strands of research, that additional resources are required to deliver on the support requirements for unpaid carers. However, no overall consensus was reached by this group, or from the other strands of the research as to how the resource pot could be increased.

Carers also requested direct measures to support carers as providers of a caring

<sup>16</sup> See Appendix 2: Report of Review of Research and International Case Studies. The five case studies were Germany, US, Australia, Finland, Denmark.



service which are not perceived as 'benefits' (e.g. carer income irrespective of age, pension credits for carers forced to reduce employment). A detailed investigation of these matters was outside the scope of this research. However, there is considerable support for an investigation into carer focussed solutions to these issues.

*'You know, the government is always talking about caring for carers. Well, they are not doing a wonderful job. I gave up my job to look after my husband and I did get a Carers' Allowance. Then I became 60 and got my pension. This is a known. I should look after my husband. It is my duty. If you can't look after your husband, who can you look after? But, for my age group, our pension was not good, because we got poor advice in the 70s. My pension is something like £37 or something to that effect. That is what I get. They stopped my Carer's Allowance. I am getting older. I've got quite bad osteoporosis of my own. I am trying not to moan about it. Life is getting harder for me to run a house, look after my husband and my grandchildren. My personal money is limited. That is my lot. I try not to be a burden on social services. I don't even take all the respite.'*  
(Carer in her 60s, Inverness)

## Employment

One of the key findings of our research is that there is an emerging gap between much of the quantitative projections of the overall demand for care and expectations about becoming a carer, a mismatch between demand and expectations, making balancing care and work critical. Our review of the literature confirmed that<sup>17</sup> projections of the numbers of people required to undertake caring roles to meet rising needs consistently show rising trends. Conversely, one of the key findings of the household

survey was that the majority (72%) of respondents felt that it was unlikely that they would become carers within the next 10 years (this includes 38% who said that this was not at all likely). Approximately one in seven (15%) respondents said that it was either very or quite likely.

The role of unpaid carers in society becomes more crucial than ever against the background of these demographic changes and challenges. A major challenge for the future is how to enable people to balance care and other responsibilities, especially work. Few carers consulted in our research reported a positive experience of being supported to balance work and care. However, some evidenced that progress in this area is possible.

*'They were great. They were really, really good in that I went to their welfare services and talked to them about my position at home and at work. I didn't know whether I was more stressed at work or more stressed at home. So, I really wanted to continue working because I felt that at least when I was at work I wasn't thinking about the problems I had at home, or how my husband's illness was progressing. So, being at work was really quite good. So they did support me in that they let me work sort of part time and I did that for maybe six months before I stopped work (retired) and that just led to me stopping work altogether... I think they support their staff quite well. I found that they support their staff quite well over a number of years because when my Mum was ill and she died, my husband was just starting with his illness and then they were quite supportive to me as well.'*  
(Post Office worker, caring for her husband who is in residential care, North Ayrshire)

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<sup>17</sup> See section on review of literature on economic modelling the future of care in Appendix 2.

There is an urgent need to increase awareness amongst employers and their representative bodies (e.g. trade associations, industry bodies) about the personal and collective (economic) contribution made by carers, and the range of measures which employers might consider introducing to assist unpaid carers of working age to balance work and care. Through our research, we were able to identify considerable challenges for carers in work, trying to combine the caring role with employment, and for carers seeking to enter or return to work. The participants in the focus groups voiced a number of concerns about the working conditions faced by carers. These include the lack of flexible working practices to enable carers to combine work and care, the problem of discrimination faced by carers seeking to enter work, and the lack of acknowledgement amongst employers about the specific needs of carers. These concerns appear to be supported by other research into the caring experience, with the problem of carers giving up work in order to fulfil their caring duties or being unable to work due to the physical and emotional pressures of caring.<sup>18</sup> The following actions are considered likely to enhance the ability of carers to balance work and caring or re-enter work:

*'I tend to choose hours when my children are at school and that was the problem with my last job although he allowed me to work from my house. There was still an issue about working overtime. He wanted me to work late and I couldn't do it. It meant that I had to get somebody to look after my bairns and it defeated the object because I had to pay for that and it takes most of your money. In the end we had a big argument about it and I said you know what you can do with your job.'* (Gas Fitter, caring for two children, Edinburgh)

- The promotion of 'carer-friendly' policies in work
- The identification and dissemination of good practice examples of employers promoting policies for carers
- The introduction of better paid leave for carers who have to take on shorter-term caring responsibilities.
- The extension of home working opportunities to working carers.

*'I love my job and I chose it before I had any caring. I chose the job because I wanted to be at home and bring up my own kids and I like what I do and I find now that it is very easy within what I do to organise my own life so that the caring doesn't conflict.'* (Childminder, caring for her mother in law, Glasgow)

The above actions could be further enhanced through a review of tax credits and benefit entitlements of carers together with the benefits entitlements of those in need of care to ensure that barriers to work are removed for those who wish to balance unpaid care and work. This appears necessary, given that the survey of carers, subsequent interviews and focus groups, consistently highlighted carers' frustrations with the tax and benefit entitlements system, which appeared to them over complex, insufficient and currently oblivious of the specific needs of carers.

There is also a need for an exploration into the perceptions of employers about the workforce development issues they face in relation to unpaid carers as employees generally, and specifically issues such as the application of paid leave for unpaid carers.<sup>19</sup>

*'I probably wouldn't have gone into youth work. Um, it's just because I can only work a couple of hours because of my caring role. I think I put a lot onto my mum with the babysitting and that, so I*

<sup>18</sup> See appendix 2: Report of review of research and international case studies.

<sup>19</sup> See appendix 2: Report of review of research and international case studies.

*think a couple of nights a week and the odd weekend is enough for her to watch my son. I would actually have liked to have been a teacher.'* (Sessional youth worker mother caring for her son, Edinburgh)

**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**

**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
- a 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.

## Services and support

The vision:

- By 2014, carers will feel well supported and have a statutory entitlement to regular breaks from caring, with the cared for person, and have ready access to local practical support
- Greater use will be made of new technology to support unpaid carers
- By 2014 all unpaid carers will enjoy better general health and well being
- By 2014, unpaid carers will be able to access a range of support provided by local community initiatives
- Unpaid carers will be properly supported to take on the responsibilities associated with a shift in resources and purchasing power associated with measures such as direct payments/cash for services, and individualised budgets

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. Almost all of the carers surveyed observed that the current level of support and service provision was inadequate, although many felt it had improved markedly in recent years, and particularly since the implementation of the national carers' strategy. More specifically, there was concern raised by participants in focus groups that carers were not afforded sufficient opportunities to influence which services they were given, with many describing the carer assessment procedures as 'top down' and prescriptive. This research uncovered an urgent call for many services to be both expanded and improved.

## Underpinning principles for service and support

There are three points that underpin all of the findings identified in relation to the services and support, which should critically inform future policy options. They resonate

with previous recommendations and it is felt important to reiterate them in relation to services and support:

- Regardless of the type of service required, it is critical that carers receive a service which is tailored to meet their individual needs. To make this happen, assessment processes need to be more interactive and holistic, giving carers the opportunity to determine more fully what they need.
- Channels of communication between the carer and the service provider and professionals need to become more open and reciprocal, with carers able to challenge the views of professionals, and professionals should be able to be transparent about resource limitations
- Equity of support across Scotland. The research indicated that some areas in Scotland provide more flexibility and quality in the services and support available than others.<sup>20</sup> There is therefore a request that the Scottish Executive, key statutory agencies and regulatory bodies monitor this situation in order to avoid the 'post code lottery' of service provision.

*'There are some areas of Scotland which are miles ahead of others in providing services to carers. This means that some areas lag behind. For those living in areas with poorer services, it isn't fair.'* (Carer representative, Perth)

### Respite and breaks

Our research has highlighted that the availability of respite provision remains patchy across Scotland, and unpaid carers often cite a difficulty in accessing appropriate respite through health and social care agencies.<sup>21</sup> For instance, when asked to comment about the future provision of services over the next ten years, carers placed access to care breaks and

outings for the people they care for as a top priority.

*'Respite breaks give the carer a day to themselves.'* (Respondent, Voices of Carers Survey)

*'There is a need to make access to respite care easier and fund more respite care, especially for long term carers.'* (Respondent, Voices of Carers Survey)

There is a need, given the scale of concerns raised about breaks and respite, for this issue to be addressed as a matter of priority. A way forward that has been frequently suggested during the research, is the development of a national framework for respite care which will ensure consistent, high quality provision across Scotland.

### Practical support

One in ten carers respondents in the Voice of Carers national survey stated that they would like more practical support. Examples include the provision of help with paper work and bills, help with cleaning, and help with undertaking adaptations to the home.

*'It would be nice if there were more practical help available - someone to get our food, help with odd jobs, etc - it is the simple things which really make a difference to my life.'* (Carer with mental health problems, Glasgow)

The practical support that carers require might be planned and/or reactive and so flexibility, and control by the carer, is likely to be key to the appropriateness of the support provided. Many carers spoke positively of the practical support they received from a range of agencies, whilst recognising that in some senses they were 'lucky' as support of this nature is not universal. Any extension of the range of practical support (e.g. low level domiciliary care) to carers delivered in the future will have considerable resource implications.

<sup>20</sup> See especially focus groups and 1:1 in depth interviews with carers in rural settings.

<sup>21</sup> For example, respondents to the national survey of carers highlighted respite and short breaks.

## Support for healthcare needs

An important issue for carers is the maintenance of their good health and general well-being to enable them to fulfil their caring role adequately. The voices of carers survey and focus groups, previous research, all unearthed widespread concern about the impact of caring on the health of carers.

The survey of carers found that 84% of carers reporting being 'tired' as a direct result of their caring responsibilities, while 74% felt stressed, and 70% had difficulty sleeping. Recent research found that over a quarter of carers providing more than 20 hours of care a week suffer from depressive illness such as stress and that carers are far more likely to suffer mental health issues or depressive illness if they do not receive periodic respite breaks. The impact of the poor health of carers on the wider NHS, and those they care for, is likely to be considerable (cf. the Kerr Report) and further research may be required to explore these knock on effects in more depth.

This overall concern for the health and well-being of carers has recently been reflected in Professor David Kerr's Report on the future of the NHS in Scotland, making five specific key recommendations for carers:<sup>22</sup>

- 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
- Building 'carer awareness' into professional training.

Therefore, to improve the health and well-being of unpaid carers, statutory health agencies should ensure that carers' health and well-being remains a key public health

issue. This should happen for as long as it is clear from research evidence that unpaid carers experience poorer health and well-being outcomes than the rest of the population.

In keeping with the knowledge that unpaid carers represent Scotland's largest 'care force' it would be useful to ensure that they are entitled to the same health preventative measures that are afforded to those in a paid caring role. Actions to support this should include free annual health checks and inoculations, and a greater emphasis on early identification of carers to ensure the effectiveness of early intervention and prevention of illness. The literature review, detailed in Appendix two, is able to highlight some examples of good practice in this area.

For many unpaid carers the GP is their first point of contact and the first to identify their health and social care, and other needs. It may therefore be useful that GP representative bodies contribute to the growing evidence base which demonstrates the positive benefits of the GP role in the early identification of unpaid carers. Efforts to bring about a closer integration between carers' information workers and GP primary care services (e.g. co-location) may also directly benefit carers.

## Counselling and psychological support

We know from previous research that many carers experience periods of isolation and/or stress, which may result in a depressive illness as a result of their caring situation. This research has corroborated existing research and has also uncovered the physical and mental impact of ill-health associated with the unpaid care task. This can be exemplified in the physical strain associated with moving and handling, as well as the emotional impact of caring and resultant social isolation.<sup>23</sup>

<sup>22</sup> The Kerr Report, (Chapter 5: Self-Care, carers, volunteering and the voluntary sector: towards a more collaborative approach), NHS, 2005.

<sup>23</sup> See particularly ranking of effects of caring on health and well-being in Appendix 3: 'Voices of Carers': Report of National Survey of Unpaid Carers and key findings of Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

Our research has identified a strong need for more counselling services, for individuals or families, to help children as well as parents cope with the demands of caring.

*'I find at times a person can get down, and we get down as well, but we've got to just stomp ahead [and] get on with it. You know, with the caring and everything else and sometimes, you want that time away just to relax or even just to talk to someone about what you're going through because you could have issues as well. You do get depressed and lonely at times when you don't have any other outside help and it's just you on your own. It's nice if you've got extended family and everybody chips in and helps but when you are on your own and you are looking after that person solely you do get exhausted if you are doing the same thing day in day out.'* (Woman caring for her father, Glasgow)

*'I had always been a bit cynical about things like counselling. The GP said to me three months after my husband died I think you would like to speak to our counsellor. That made a huge difference. She wasn't somebody close to me, or family or a friend. It was a tremendous difference to me. She was able to take a sort of impersonal view of things and stand back. Sometimes you just want a person to talk to quite honest.'* (Carer, Inverness)

### Aids and adaptations

Access to aids and adaptations is also emerging as a key issue for carers. Carers identified the need for aids and adaptations to be more accessible and visible<sup>24</sup> (e.g. in high street show rooms and on line stores). However there is acknowledgement that there is a need for professional advice, with the proviso that aids and adaptations will be available without unnecessary bureaucracy.

### New technology

This was identified as a key future driver in the support for unpaid carers and the provision of services to those who are cared for, in several of the research strands (Stakeholder Steering Group, Delphi Survey<sup>25</sup>). 'Telecare' is the application of technology to caring as a complement to traditional forms of care which can support choice and flexibility of service provision, and has the huge potential to support a diverse range of individuals. Telecare may prove to be vital to supporting the contribution that unpaid carers make. Specific consideration should be given to the role of 'telecare' in the development of policy and services for unpaid carers. Therefore carers and their representative organisations should be consulted about the scope for the application of telecare.

### Issues for specific groups

Carers are not a homogeneous group. Specific groups of unpaid carers, most prominently young carers, black and minority ethnic carers, and carers with learning disabilities and with mental health conditions, as well as older carers, require different responses from agencies. The focus groups and interviews were able to highlight a range of specific and different issues and needs for these groups.

#### 1. Young carers

A young carer can be described as a child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability. The definition used in the Young Carers' Good Practice Guide published by the Princess Royal Trust for Carers is:

*'A young carer is a child or young person carrying out significant caring tasks and assuming a level of responsibility for another person, which would normally be*

<sup>24</sup> Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

<sup>25</sup> See Appendix 1.

*taken by an adult. The term refers to children or young people under the age of 18 caring for adults (usually their own parents) or occasionally siblings.'*

The research has consistently uncovered that young carers face specific challenges, in undertaking their carer roles. The review of literature found that this group, as compared with other groups of carers, appears to be consistently under researched, making it difficult for carers organisations to identify their needs and respond to these. Our interviews with young carers also found that some young carers feel particularly high degrees of isolation and detachment from mainstream society. Research also tells us that, compared to other carers, young carers are less likely to have had a carers assessment.

## *2. Black and Minority Ethnic (BME) carers*

While the impact of caring on BME carers is similar to other groups, there are still felt to be cultural, institutional, and language barriers which make access to services more difficult than for other unpaid carers.<sup>26</sup>

*'I think most of all it is the language that is the barrier and the difficulties with the nurse and things but I find in the last stages, you know ... I care about my mother over ten years. I look after her at home. I have to do everything for her, bath, cooking, everything. But in the last stage, I take her to the nursing home because I really can't take care of her. But the time she stay in the nursing home, it is very difficult. I have to be there anytime, 24 hours because the nurse don't know what she talking about and she don't understand. So, I end up with a telephone next to her bed because you have to support yourself, they don't support you.'* (Chinese woman who formerly cared for her elderly mother, Edinburgh)

Support services which may be effective for most people may be inappropriate for some sections of the community (e.g. some forms of respite and day care). Models of care based on cultural assumptions that are relevant for some sections of the community need critical evaluation before they inform the development of services for other sections of the community. Including black and minority ethnic communities in the planning and delivery of care services is directly implicated here. Continuing professional development must also enable a critical reflection on 'Eurocentric' models of care and support to ensure that carers from BME groups are included more readily as partners in care.

## *3. Carers with mental health issues*

Being diagnosed with a mental illness can lead to a feeling of stigma and discrimination. And carers with mental health issues reported that stigma can be a complicating factor to the issues already faced by most unpaid carers. It is important therefore that carers with mental health problems are supported to communicate their needs and are acknowledged as more than their mental illness but also as providers of care. Their capabilities as carers should not be negated by the diagnosis of mental illness but additional support made available to ensure that they can carry out this role successfully. This includes support to communicate needs and challenge working assumptions. Carers with mental health issues in particular cited a lack of information and confidentiality issues as key concerns for the future.

## *4. Carers with learning disabilities*

The research also highlighted that carers with learning disabilities can often find it hard to articulate their needs and get professionals to recognise their role as

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<sup>26</sup> See particularly key findings of Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

carers. This is a particular issue as our research has found that carers who face difficulties expressing their needs, often receive poorly coordinated services.<sup>27</sup> Carers from this group reported difficulty negotiating access to respite, and navigating their way through what is perceived to be a complex web of interrelated benefits entitlements.

### The role of carer organisations and the voluntary sector

Throughout the study, carers and former carers commented on their experiences of statutory and voluntary agencies as providers of support. Many carers found the route to information, advice and emotional support through local voluntary sector carer organisations easier and more accessible than direct approaches to statutory agencies.

However, the roles and responsibilities of different sectors were understood, and the criticism of service provision and assessment processes by statutory agencies was often balanced by an understanding of funding constraints and competing priorities. The research found that carers often experience voluntary sector support as less bureaucratic and stigmatising and more person-centred, although those who receive comprehensive support from statutory agencies did praise the services they receive.

There was universally high praise for the voluntary sector in its role as a major provider of services to carers, including local carer-led groups such as Princess Royal Trust Carer Centres, and other not for profit and charitable providers. In particular, research participants were able to point to the high quality of support offered by voluntary sector agencies through caring support groups, information provision, advice on legal matters and rights,

emotional and practical support in daily life, advocacy and befriending schemes.

However, concerns were also voiced about the sector lacking the capacity, knowledge and expertise required in some instances necessary to fulfil its role. Many of these organisations in the sector are small, lacking core funding and resources. Therefore it is unsurprising that these concerns were raised. The research highlighted that to maintain the positive function of the voluntary sector support to carers, it is important to build the capacity of the voluntary sector, and increase its professionalism.

It was also felt that carer representative organisations, whilst individually effective communicators of the carer's needs, could benefit from combining their efforts in some way to ensure that the views of carers are more effectively communicated at a national level.

Some proposals which are likely to enhance the role of the voluntary sector to work in partnership with statutory organisations locally include:

- The development of 'compacts' between community and voluntary 'umbrella' organisations and local statutory agencies setting out funding arrangements and expectations on service delivery to carers locally.
- Longer contractual arrangements with individual carer and voluntary organisations, making funding more stable, without undermining the principles of 'best value'.
- Increased representation of carers' organisations on local decision making forums, such as Community Planning structures.
- The development of local 'carer partnerships' which pool the experience

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<sup>27</sup> See specific issues for carers with mental health issues and carers with learning disability in Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.



of frontline professionals from all sectors and thus maximise the contribution of each, for local carer benefit.

**Recommendation 16: We recommend that the Scottish Executive, Local Authorities and NHS agencies along with partner agencies, focus strongly on the health and well-being 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 recommendation 16, 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.

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

**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
- 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.

**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.

**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

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

## Resourcing

The vision

- By 2014 carers will be partners in the provision of care and will benefit from adequate financial advice and resources to support their caring situation
- Sufficient resource will be available to statutory agencies and independent sector to facilitate equitable support to unpaid carers and services to those who require them

A common theme which emerged out of the research was the requirement for sufficient resourcing for support services for unpaid carers and those they care for. While many

involved in this research (carers and others) commented that services had improved in recent years, there was an articulation that greater investment will be required to deliver on existing promises and fulfil need. This was strongly articulated by those in the statutory sectors who advised of the number of competing priorities on the limited resource available to them. The requirement for additional resources was identified as one of the robust actions at the scenario event that is likely to hold regardless of the particular circumstances any future scenario may present. That is, there was a strong and broad consensus for a sustained effort to consider the resource implications of a more positive future for carers, and that the issue of increasing the levels of investment into carer related services needed to be investigated further by both the UK Government and the Scottish Executive.

## Implementation and performance

The research uncovered strong concerns from unpaid carers that although new policies may be created they may not be effectively implemented on the ground.<sup>28</sup> 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. Therefore, it is important that organisations with a regulatory, quality assurance and inspection function, more effectively monitor the implementation of policy to ensure there is not a gap with practice.

*'Much of the policies are in place. These emanated from the last carer's strategy. However, there appears to be inconsistent, and patchy, implementation of these strategies.'* (Representative of carers, Edinburgh)

<sup>28</sup> See particularly Appendix 4: 'Voices of Carers': Report of focus groups and in depth interviews with unpaid carers.

In particular, this research has highlighted the need for closer monitoring of the levels of carers' assessments undertaken. Health and Social Work inspection bodies should, for instance, treat as seriously the failure of local authorities and health agencies to undertake carers' assessments as they would any failure to undertake the needs assessment of those who are cared for.

Other areas of inconsistency in the quality of service delivery that were highlighted include the following areas:

- The extent to which carers information strategies are implemented and monitored
- How effectively the health needs of carers are properly diagnosed and these needs are met
- The availability of local information about services and how to access them
- The extent to which carers and carers representatives are involved in decision making about service design and delivery

**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.

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<sup>29</sup> *ibid.*

# 3

## Section Three



### Recommendations for further research

There are a number of areas identified, primarily from the review of research, that merit further investigation.<sup>30</sup> These are set out below for specific groups and further highlight the diversity of the unpaid caring population. However, there is also a general recommendation that good policy needs to continue to be based on good research in relation to unpaid carers.

Generally, there is a need for:

- Longitudinal research into the experience of caring. This is likely to include studies which take a 'life course' or 'cohort' approach (following a particular group or sub group over time) and which couple this with an emphasis on the effectiveness of range of interventions over time
- Research at the local level on referrals and assessments processes. In particular, whether inter-professional referrals are more likely to result in better access to services, better services or higher levels of provision, the use of single shared assessments and their impact on service provision, the experience of the carer and cared for.
- Research on how unpaid caring affects the employment relationship – perceptions of both employers and unpaid carers.

- Research on the links between volunteering and unpaid care:
  - who volunteers formally and who does not?
  - what are the motivations, benefits, actions required to improve their experiences to encourage volunteers to stay volunteering?
  - what are the barriers which stop non-volunteers becoming involved, and what actions might influence their attitudes?<sup>31</sup>

We outline below recommendations for further research relating to specific groups.

#### Young carers

Confirming recent and more thorough research reviews, our review was not able to identify any randomised clinical trials (RCTs), longitudinal studies, meta-analysis or systematic reviews of young carers. The existing research base is good on describing the characteristics, experiences and needs of what had been a hidden group of children; it is less developed on 'causes' and 'effects'. Why do some young carers experience educational problems, while most do not? Research is needed which focuses on resilience and how this might affect outcomes for young carers and their families, rather than just 'vulnerability'.<sup>32</sup>

<sup>30</sup> See also Appendix 2: Report of review of research and international case studies.

<sup>31</sup> Strategy for Volunteer Development: Review of Literature and Research, Danson, M, 2005.

<sup>32</sup> Becker, S., Review of research on young carers, presentation to 'Supporting Young Carers - A Future Through Partnership' conference, Edinburgh, 6th June 2005.

*'I missed school at times. I felt lost and on my own. When the kids I went to school with spoke about cartoons, I had no idea what they talked about. I felt nobody understood me. I didn't even feel comfortable talking to the doctors.'* (BME man caring for his mum since being a teenager, Edinburgh)

There are no UK-based studies of young carers caring for parents with HIV/AIDS or those who misuse drugs or alcohol, or those living in asylum seeker/refugee families.

More research is needed which compares the experiences of different groups of children in need (including young carers) and contrasts these with a 'normative' group of peers.

*'I used to find it hard and then my mum had to go into hospital and I had to take time off school, and I missed all of primary 5 and then I had to go to my Gran's and I missed all of what my teachers were teaching and I failed all my tests, but now I am back to credit classes.'* (13 year old girl, caring for mother with depression, Irvine)

Research is needed into 'cycles of disadvantage': Is the health, well-being and development of young carers affected more adversely when they experience a clustering of negative outcomes or disadvantages?

More research is needed on evaluation and effectiveness: what really works for young carers and their families?

Research needs to tell us more about young carers and other vulnerable children who don't receive services and support, i.e. unsupported children. The quality of health and social work services is important in determining outcomes for children who receive them, but it does nothing for those children who don't.

## Black and minority ethnic communities

The quantitative carer (and former carer) survey undertaken for this research was the largest ever undertaken in Scotland. However, the results for BME groups have to be treated with caution because of the relatively small sample size from these groups. Clearly this may have been a result of the fact that the survey was distributed with the assistance of carer organisations and either not enough of these were in touch with people from BME communities, or the response rate was lower for other reasons. In any case, there remains a significant gap in our understanding of the current experience and future aspirations and preferences of unpaid carers from BME communities in Scotland.

*'They are not joining those groups because they can't speak English. Since they do not speak English, they do not know that there is a group there and even workers working with them who introduce these groups, they are very reluctant to join because if they were there, they can't communicate with other parents so there is no point them being there.'* (Father caring for son with cerebral palsy, Edinburgh)

## Lesbian and gay carers

Very little appears to be known about the experience of same sex carers. In the absence of suitably robust evidence from which to inform national policy for these groups, it is recommended that further research into the specific needs and care experiences of lesbian and gay unpaid carers be undertaken. This is not to suggest that their needs might be different but to highlight that they may face the additional barriers of a lack of legal recognition, prejudice and therefore risk greater social isolation and inappropriate services.

Wherever possible, further research should be conducted with a Scottish specific focus.

It was a key finding that although a good body of Scottish specific research on unpaid care exists, there is a larger body of UK-wide literature, and we recommend this imbalance be addressed over time.

Some of the gaps identified by this research may have already been addressed within the Scottish Executive or elsewhere. However, it seems plausible that the Scottish Executive is best placed to co-ordinate efforts to commission, review, and update the evidence base relating to unpaid care. However, in our experience the best research is often undertaken in partnership with those agencies that are already in touch with carers. That was the experience of this research where many community, voluntary, and statutory organisations assisted the distribution of the large scale survey to approximately 25,000 carers, directly enabling a high response rate and raising the profile of the Scottish Executive's attention to this important policy area.

**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.

# 4

## Section Four



### Summary of recommendations

Overall, the research has made a number of significant gains in taking forward a consideration of the future role of and outcomes for unpaid carers.<sup>33</sup> It is the first time that unpaid care has been the specific focus of a 'futures' research project in the UK or Europe. It is anticipated that the recommendations within this report will consolidate existing thinking on support for unpaid carers, whilst also creating new solutions for the future. The research concludes that if the recommendations within the report are implemented the future for unpaid carers in Scotland will be a positive one.

- 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.

### Summary of recommendations

**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.

**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

<sup>33</sup> There are a number of outputs from the research which should continue to serve as a resource for stakeholders (carers' organisations, local authorities, health agencies, the Scottish Executive, Westminster government, and other interested parties) to utilise beyond the scope of the research project. These include all the data sets (quantitative and qualitative), a 'tool kit' for conducting focus groups with unpaid carers, an economic modelling tool designed to look 10 years ahead and with the functionality to replace the core data sets on which it is based, and to put an economic value on unpaid care, questionnaires and other survey instruments which can be utilised at later dates, and a review of research incorporating comparative international cases studies.

- 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.

**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.

**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.

**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.

**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

**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**



**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.

**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**

**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**

**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.

**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.

**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**

**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.

**Recommendation 16: We recommend that the Scottish Executive, Local Authorities and NHS agencies along with partner agencies, focus strongly on the health and well-being 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 well-being from the Kerr report are considered as mutually reinforcing to those made here.

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

**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
- 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.

**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.

**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

**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.

**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.

## Annex One



### Policy and context - the story so far<sup>34</sup>

The starting point for the development of a Carers Strategy in Scotland was the UK Strategy, 'Caring for Carers', launched in February 1999. The UK Strategy heralded, for the first time in the UK, a substantial policy package for unpaid carers and it put carers' issues firmly on the political map. This was despite the fact that the first real legislative rights for carers, primarily the right of 'regular and substantial' carers to have their needs assessed as part of an assessment of the overall needs of the person being cared for, had been put in place under the UK-wide Carers (Recognition and Services) Act 1995. Implementation of the 1995 Act was patchy throughout the UK and given low priority, in Scotland primarily because of the sizeable impact at that time of local government reorganisation.

Following elections in May 1999, the first Scottish Parliament since 1707 took up its new devolved powers, which included responsibility for health and social care. One of the earliest policy documents to be produced by the new Scottish Parliament was the 'Strategy for Carers in Scotland', launched in November 1999. The Scottish 'Carers Strategy' mirrored the commitments set out in the UK Strategy and set a framework for delivering those within a Scottish context.

The Scottish Carers Strategy highlighted the vital contribution made by unpaid carers and set out a national commitment to supporting

carers, bringing carers and carers groups into the policy process locally and nationally, and making local authorities more accountable to the Scottish Executive and users and carers. The strategy specifically targets young carers and provides a commitment to greater levels of training on the needs of carers for staff in local authorities, social services and the NHS.

As a direct result of the Strategy, there were several significant legislative developments within Scotland. The Community Care and Health (Scotland) Act 2002 is one of several milestones in ensuring that carers are adequately recognised and supported by local authorities and the NHS within Scotland. The Act provides a universal entitlement for carers to request an assessment of their needs, independent of any assessment of the dependent. Essentially, it recognises carers as 'providers of care' with a need to access adequate support and resources, rather than another group of 'service users'. The Act allows carers to be the focus of local authority and social work resources and it cements the centrality of the role of unpaid carers as 'co-producers' of outcomes. Significantly, subsequent guidance to the Act formally recognised carers as key partners in the provision of care. This change of status formalised a partnership approach with carers that already existed in a few forward-thinking areas of Scotland as a result of the

<sup>34</sup> OPM acknowledges the help of Care 21 and the Scottish Executive's Social Work Services Policy Division and Carers Branch for their contribution to this section of the report.

Carers Strategy, and sought to standardise that approach nationwide. This re-conceptualisation of carers has yet to be mirrored elsewhere in the UK.

The 2002 Act and subsequent guidance continued the existing legal definition of a carer (someone who cares on a regular and substantial basis) and applied this to the new right to a formal and independent assessment of the carer's support needs. However, it also sought to promote early intervention as a means of preventing future break down of the caring relationship, through the early provision of information/advice and practical support. The 2002 Act also extended the scope of direct payments, allowing some parents, guardians or carers to receive payments on behalf of the dependent, which increased their ability to access more flexible support.

The 2002 Act takes the carers' agenda to the very heart of the NHS in Scotland through the proposed introduction of NHS Carer Information Strategies. Although not yet implemented, the strategies should put in place long-term mechanisms for identifying carers in primary and acute settings and ensuring that they are provided with appropriate training and information to help them with their caring role, either by the NHS directly, or by NHS staff signposting carers to appropriate sources of advice and support. This is expected to have significant benefits in ensuring that carers are identified and supported as early as possible and at key stages in their caring role.

The need for the NHS to play its part in supporting carers is recognised in key health policy documents, the most recent being 'Building a Health Service Fit for the Future' (2005). This report, also known as the 'Kerr Report', sets out a 20-year plan for the NHS and shifts the emphasis from hospital-based care to preventative, anticipatory care rather than reactive management. It recommends full implementation of NHS Carer Information Strategies as a means of helping to protect the health of unpaid carers and in assisting them to provide effective care in the community.

The 2001 Regulation of Care Act established the Care Commission and set in place the legislative framework for the development and monitoring of national care standards. This included the setting and inspection of national standards for respite services and care at home and housing support services.

In Scotland, there is also a concerted drive to deliver more integrated health and social care. The recommendations of the 'Joint Futures Group' helped shape the future of health and social care policy in Scotland, concentrating on the need to improve joint working, between the NHS and social work but also between the statutory and the voluntary sectors. The aim is to provide single shared assessments, integrated services, quicker and faster decision making, and service provision. The development of Community Health Partnerships is also in line with integration and focus on linking services and planning processes to address the wider health needs of communities.

Further to the integration agenda, the Scottish Executive has recognised the need for change in the delivery of social work services to adapt to changing demographics and public expectations. As such, the 21st Century Review of Social Work Services chaired by William Roe, has been tasked with producing the most fundamental review of social work services since the Social Work (Scotland) Act 1968. All recommendations from this exercise will be forwarded to and noted by the Social Work Review Group.

## Links with emerging UK-wide health and social care policy

The Adult Social Care Green Paper for England and Wales, 'Independence, Well-being and Choice', anticipates greater personalisation and choice for service users and includes positive messages about user empowerment. However, compared to carer policy in Scotland and emerging messages from Care 21's report on the future of unpaid carers, the Green Paper appeared to fall short of fully recognising carers as key

individual care providers and as the UK's largest care force. It seemed to perpetuate a perception of unpaid carers as another client group with demands for 'services' rather than as a provider group.

Care 21's report implies that the vision for building greater capacity for social care will not be possible without adequate recognition and support of unpaid carers as knowledgeable, experienced and highly flexible care providers. The Health and Social Care ('Care Outside of Hospital') White Paper due in England and Wales later this year is expected to pick up where the consultation around the Adult Social Care Green Paper left off. Care 21's report on the future of unpaid care in Scotland may be timely for

consideration of policy developments in England and Wales.

Efforts are required to preserve the achievements of the Green Paper on user choice and personalisation whilst also building a more rounded agenda, involving broader considerations of prevention, well being and independence, which draw on a range of contributions: local authority services, the community and independent sector, and not least unpaid carers.

In summary, comparing the carer dimension in recent strategic reviews in England and Scotland (e.g. Green Paper and Kerr Report) shows that recognition, partnership and joint working with carers currently remains more integrated in Scottish social policy.

## Annex Two



### List of separate appendices that accompany this report

Taken together the following reports constitute the evidence base for this research.

Appendix 1: Planning for the Future of Unpaid Care in Scotland-note of event proceedings, 26 August, 2005

Appendix 2: Report of Review of Research and International Case Studies

Appendix 3: 'Voices of Carers 1': Report of a National Survey of Unpaid Carers in Scotland

Appendix 4: 'Voices of Carers 2': Report of focus groups and Interviews with Unpaid Carers in Scotland

Appendix 5: Report of a National Household Survey in Scotland on issues relating to Unpaid Care

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