



The Future of Unpaid Care in Scotland

APPENDICES 1-5

“1 in 8 are carers”

The Future of Unpaid Care in Scotland

HEADLINE REPORT AND RECOMMENDATIONS



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Summary of the research methodology

Exploring the future of unpaid carers in Scotland

The support needs of unpaid carers have rightly become an important policy area in Scotland. Between October 2004 and August 2005, the Care 21 unit within the Scottish Executive, together with the Office for Public Management (OPM), a leading public sector research and consultancy organisation, undertook a project looking into the future needs of unpaid carers, and how services might need to change over the next 10 years. The project involved working with carers, carer support and statutory organisations engaged in the delivery of services for both service users and carers.

A summary of the project

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 2014¹
- 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.

¹ This strand of the work was developed in partnership with Experian Business Strategies, a specialist econometric research and consultancy organisation.

The future of unpaid care in Scotland

- 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.

The appendices within this report form a summary of much of the strands of research within the methodology.

Appendix 1:

**Planning for the future of unpaid
care in Scotland – note of event
proceedings, 26 August 2005**

Introduction

This is a report of an event held on 26 August 2005 at Murrayfield Stadium, as part of the research on the future of unpaid care in Scotland, undertaken by OPM, and commissioned by Care 21, a social work innovation unit located within the Social Work Services Policy Services Division of the Scottish Executive. A full note of the various strands of this research is set out at section one below. Section two describes the proceedings. Section three presents a summary and conclusions. There are several annexes containing the materials developed to make the event a success.

This event had a dual purpose. First, it was the fourth (and final) meeting of the Stakeholder Steering Group (SSG) for the whole project. The SSG had previously met three times over the course of the research. Its role was to oversee progress, receive interim results and act 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. It formed the core participants for the stakeholder event.

Secondly, and more importantly, the event marked the end of the research project by bringing together over 60 participants² (including the Stakeholder Steering Group) from a range of diverse backgrounds, but with common purpose, to:

- **Build greater consensus around an emerging vision** for unpaid carers (see annex A). This emerging vision was a synthesis of the research findings and other work, including legislative and policy commitments already made. Participants were asked to validate or challenge elements of the emerging vision.
- **Consider three plausible futures** for the context in which unpaid care might take place in 2014. The plausible futures used here are included in full in annex B. The scenarios themselves were derived from a synthesis of the research findings emerging from the other strands of the research described below in section one, and in particular were the result of an multi-staged 'organised brainstorming' research technique known as a 'Delphi survey' (see methodological note at annex C).
- **Uncover opportunities and challenges** in each of these scenarios.
- **Identify 'robust actions'** as a basis for planning for the future of unpaid care in Scotland. Robust actions in the context of scenario planning are those actions or recommendations **that if taken forward, will prevail in all of the scenarios**; that is, they are thought to hold for multiple possible and plausible futures, and are therefore strongly consensus based.

² See annex D

There is real value in this type of ‘what if?’ thinking. First, it helps us to devise medium-term contingencies for action, just in case what everyone assumes will happen does not. Secondly, and more importantly, it helps us to understand what sorts of actions will be necessary, whatever happens in the future; these are actions that will remain robust throughout a range of possible future developments.

Robust actions for the future of unpaid care in Scotland

The robust actions identified were:

- Unpaid carers (or carers’ organisations) should be more closely involved in shaping service delivery and planning.
- There should be better engagement with unpaid carers.
- There is a need to change wider societal attitudes about unpaid carers – especially amongst professionals, concerning the expertise that carers have to offer.
- Caring as a ‘problem’ needs to be reframed as a positive life choice for many and a valuable resource to society. This needs to be reinforced, particularly outside the health and social care domain, in the areas of housing, transport, education, leisure, employers, and the media.
- There is a need to build voluntary sector capacity.
- There is a need for legislation/incentives (for example tax breaks) to encourage employers to recognise the rights and needs of carers.
- In relation to all of the above, more resources will be necessary.

There is also a shorter list of ‘contingent actions’ (mentioned for two scenarios only). There is a need for:

- A ‘big conversation’ about how this agenda will be resourced. Is there consensus about approaches based on tax benefits or means testing?
- Greater consistency and coherence of language around outcomes for unpaid carers.
- Better advocacy for carers, including an independent advocacy organisation for unpaid carers.
- More robust standard setting and maintenance of any national minimum standards set.

These robust actions resonate with many of the more specific recommendations in the main headline report, and should therefore be **communicated widely as part of the general communications about this research and the formal response to its findings and recommendations.**

The remainder of this report describes the process that generated these robust actions.

1. Section One: Event proceedings

This section describes the main sessions and event proceedings.

1.1 Session One: Confirming the vision for unpaid carers in 2014

The participants were given a short introduction to the day from Care 21 and Greg Parston,³ who, as chair for the scenarios exercise, explained the role of scenarios in futures and planning work. Participants were allocated to one of three groups of stakeholders: those representing the community and voluntary sector, those from health and social care providers, and those from the Scottish Executive and other policy-making bodies and research organisations.

At the first session, participants were asked to reflect on the 'vision statement' for carers in 2014, which Care 21 and OPM had developed as an emerging vision for carers in the future (see annex A). The vision describes principles relating to how carers should be treated in the future along with specific objectives describing how their lives could be improved. After discussing the vision in their specific groups, the participants raised the following issues:

'Occupationalisation'

Though the participants felt that it was important for caring to be recognised as a full-time commitment, akin to any other occupation, there were concerns raised over the idea of 'occupationalisation'. There was a feeling that such an approach risks creating a task based approach to caring which looks not at the carer but only at the caring tasks. It was felt to be important that the vision looked at 'being a carer' rather than 'doing caring' and that it was about supporting carers to be 'all that they are and want to be', rather than just supporting their caring work.

Carers in employment

There was strong agreement that the vision as it stands does not effectively cover the needs of working carers and that a separate statement should be inserted. This should assert the belief that working carers should be given all necessary support from their employers and the public sector to continue both roles.

Rights of carers

Equality of opportunity should be enshrined within the principles of the vision. It was felt to be necessary to have a strong and clear statement that caring should not prevent carers from having the opportunity to live their own lives. Participants felt that caring needs to be

³ Chair and co-founder, Office for Public Management (OPM)

thought of as an equalities issue and so documents such as 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.

Specific groups

Whilst most people agreed that it was useful to have statements relating to specified groups (in the original vision this included, for example, black and minority ethnic community groups) there was a feeling that these needed to be carefully considered. Most people felt that these specific groups should be defined by their different needs rather than simply different characteristics, and it may be necessary to include groups such as parent carers or older carers. The fear was that the process of separating carers into specific groups could continue for ever.

Specific issues

The following issues specific to individual statements were raised:

- When referring to the health needs of carers, the statement should set out the principle that their health needs would be met and their health not adversely affected by caring.
- Statement 6 should read 'receive financial; recognition, resources and advice'.
- Statement 7 should give a wide ranging right to training throughout the caring role.
- Statement 8 should include the right to take a trip or respite break with the cared for person, not simply a right to a break from them.

1.2 Session Two: Developing solutions for future scenarios

In session two, participants were asked to respond to the future scenarios of Scotland in 2014. In this session, the participants were asked to enter mixed groups and respond to only one of the three scenarios, depending on which of the three they had received prior to the event.

The scenarios describe a plausible, but imaginary, future in Scotland, based on the predictions of almost a 1000 respondents to OPM's Delphi survey (see annex C) and the results of economic modelling of the future using the modelling tool developed for this research. Each scenario describes a Scotland in terms of different demographics, economic conditions, political circumstances, the lives of carers and other social trends. Each presents very different challenges to policy makers, public services and carers. The main features of each scenario are described below:

Summary of scenario one: Prosperity for some

Prosperity for some describes a Scotland in which a right-of-centre government is aiming to change the shape of Scottish politics by shifting power away from the state towards local individuals and communities. In this Scotland the economy is strong, although key sectors of the traditional Scottish economy, such as manufacturing, are in perpetual decline.

The Scottish population is declining, with the number of over 65s expected to be double the number of under 16s within the next 20 years. While there is a strong economy with many highly paid jobs, people are expected to work later into their lives, with many choosing to work into their 70s. Public services are the focus of significant reform, with three main themes underpinning change: shift of resources to the front line, decentralisation to localities, and freedom to choose. As a result of this agenda, there have been large-scale cuts in jobs in the NHS and local government, with power shifting to front-line practitioners, and the introduction of greater choice for users of public services. In some parts of the NHS, charges have been introduced for some NHS services. In 'prosperity for some', there are higher levels of health problems compared to other developed nations, but declining mortality for cancers, strokes and coronary heart disease.

In 2014 there is a steady increase in the number of people undertaking caring responsibilities. The number of carers from working class backgrounds is increasing at twice the rate as those from middle class backgrounds. Meanwhile, the role for the voluntary sector in providing services to carers and carees is growing. There is also an increase in the number of high intensity carers and these are over-represented in lower socio-economic groups.

The number of marriages in Scotland, which briefly increased between 2006 and 2010, is starting to decline again. When surveyed in 2013, 25% of Scots between the ages of 15 and 45 reported that there was 'no such thing as society', but more people said that it is important for people to help those less fortunate than themselves.

Summary of scenario two: Inflexible cohesion

'Inflexible cohesion' describes a Scotland with a centre left administration committed to high levels of public spending, although increasingly restrained by the weakening of the economy and thus the tax base.

The public sector is booming in this scenario, with a greatly increased public-sector workforce and extension of entitlements to assistance as policy moves Scotland towards a social democratic model of state provision. Scottish public spending levels are consistently above the UK average with significant improvements to the health of people in Scotland.

However, in 'inflexible cohesion', the economy is ailing mainly because of higher taxation and wage costs in the UK, with declining spending power and wide regional variations. At the same time, the EU has strengthened European Human Rights, equalities and employment law, greatly increasing the number of legal obligations imposed on UK employers.

In terms of the country's population, the natural rate of decline in the Scottish population continues, although the administration records some success attracting immigrants from both the UK and the rest of the world, leading to significant growth in the black and minority ethnic communities and an unexpected rise in the number of under-30s in the population.

For public services, there is a consistently high level of public spending resulting in tangible improvements. Reform of public services is underpinned by two themes: investment met with excellence and building cohesive communities.

Unfortunately, in this scenario there has been a large growth in the number of people undertaking caring responsibilities. Fuelling this growth is the fact that people are living longer and are experiencing complex care problems, such as diabetes, arthritis and heart difficulties. This group, while well supported for their acute needs by the NHS and social work, require an increasing amount of support from unpaid carers.

Nationally, health continues to improve with better survival rates, reduced mortality for major diseases, including cancer, strokes and coronary heart disease, and steadily increasing life expectancy, with reduction in health inequalities. There is an increase in some mental health problems, including depression, schizophrenia and eating disorders.

In this scenario, the gap between the wealthy and the less prosperous has narrowed, but many areas are still classified as deprived, with high unemployment, crime, poor quality housing, and lower standards of health prevailing in many areas. Long-term unemployment is still a problem.

On a positive note, more people 'trust their neighbours' and 'feel part of the community', while participation in local elections has hit a 10-year high and more people than 10 years ago take part in volunteering, but this is starting to decline. However, there is increasing racial tension.

Summary of scenario three: Choice and division

'Choice and division' describes a Scotland with a centrist government committed to a programme of 'modernisation' in public services. In this scenario the economy is performing well, boosted by high levels of flexibility and a strong knowledge-driven economy in Scotland. There has been sustained investment in public services, leading to many improvements in outcomes. While there has been a decrease in poverty overall in Scotland, poverty is still prevalent in many areas. In addition, employees work longer hours and take fewer holidays, while many employers pay scant regard to European employment directives. There has been an extension of the retirement age to 70 and many health experts believe that workplace stress has reached epidemic levels.

On a positive note, the gradual decline in the population over the last 20 years or more has mostly been reversed.

Two central themes drive public service reform: 'promoting user choice' and 'building community resilience'. The reform agenda has led to more localised and professional control over primary care budgets, while more money is given directly to carers in the form of 'care vouchers'. The voluntary sector has grown markedly in size, professionalism and capability. While local authorities still provide most democratic community leadership, new neighbourhood forums have the power to develop local plans, set targets, distribute funds and promote choice by purchasing services for local people from a range of providers. The sustained investment in the NHS has produced general improvements in the levels of mortality and morbidity, but the quality of life of older people is highly correlated to income, savings and pensions. As a result, growing numbers are almost entirely reliant on the help of friends, family and local charities.

The number of carers has continued to grow across all age groups and social classes, although there has been a sharper increase in carers from lower income and socially deprived groups.

Increases in NHS and local authorities' services have not kept up with the growing numbers who need care. There is a steady decline in the level of support and provision provided by local public services for both those who need and those who provide care.

In terms of society, the gap between the most and least well off has reduced slightly but there are still huge levels of inequality. Although poverty has fallen overall, there are still pockets of severe deprivation where poverty, crime, low quality housing, and low educational achievement are concentrated. At the same time there has been a marked growth in 'individualism' and a declining support for 'society and community'. When surveyed, more people now believe that 'there is no such thing as society'. Many people point to there being a breakdown in 'mutual respect'.

Having split into three groups, each addressing one of the scenarios, the participants were asked to think through and comment on what *challenges* and *opportunities* each scenario presents. The main issues raised in relation to each scenario are described below:

Opportunities and challenges

Scenario One: Prosperity for some

The following opportunities and challenges were identified for 'Prosperity for Some':

Opportunities

- Empowerment and response to local need
- Opportunity for those with the highest needs to have them met
- Employers have greater incentive to introduce family friendly policy to attract workers
- Greater choice for those who have access to resources
- Deeper awakening of spirituality
- Young people mature earlier and have more power and influence

- Reduction in bureaucracy will free up resources
- Potential for shift in resources away from the state to the voluntary sector
- Greater recognition of front-line staff
- With GPs given greater incentives, there could be better support to carers
- More opportunity for mutual self-help between carers
- Renewal of community development led by the voluntary sector
- More focus on promoting and recognising the skills of carers
- Employers could adopt more family friendly policies
- Increased numbers of carers gives carers' movement greater clout

Challenges

- Increase in inequality and postcode lottery
- Fewer people coming to Scotland
- Less pressure on employers to improve support to carers
- Limited employment prospects for young carers
- Danger of there being a reinstatement of institutional care
- Changes in management in public services leading to inconsistent practices and reduced quality
- There will be an increased gap between high and lower performing public services
- Increased skills shortages, with fewer people wishing to enter professional caring
- Greater levels of social polarisation, with carers adversely affected
- Danger that more people will choose to pay for care rather than do it themselves
- Decrease in regulation
- Due to the decline in the role of regulation, public services face difficulties in tracking vulnerable people
- Resources directed only at 'deserving' rather than people with lesser needs
- Reduction in people's sense of well-being

Scenario Two: Inflexible cohesion

The following opportunities and challenges were identified for 'Inflexible Cohesion':

Opportunities

- Infrastructure focused on prevention – huge opportunity to improve the way statutory organisations work together. Provision of guidance to carers about how to 'take on the system' – independent centres of advice, breaking down the silos

- Remote care giving – could redefine our concept of ‘neighbourliness’ so that they are not so contingent on geographical proximity
- Joined-up approach to monitoring and improvement
- Neighbourly trust means there is a greater pool of carers
- A strengthened Human Rights Act means that there could be greater protection from discrimination on the grounds of caring responsibilities
- Community planning looks like an opportunity – but does not seem to be working in this scenario
- Broader focus needed: not just health and social care organisations, but education, housing etc.
- More carers means that there will be more carers in the workplace – might sensitise employers to the needs of carers

Challenges

- Rising divorce rate means there’s a smaller pool of partners available to care
- Suggests that ‘expert carers’ could get all the support – leading to divides amongst the caring community
- Linked to this, it would seem that the attitudes of professionals still has not changed – has yet to catch up with rhetoric around respecting the expertise of carers
- Whilst coterminous boundaries are an opportunity, there is also a threat if they become too big
- Heavy state control – not unlocking the potential of ordinary people
- Increase in employment regulation – if this does not include regulations relating to carers’ rights then this is a threat in the sense that employers will already be feeling over-burdened and are likely to be resistant to additional (carer-oriented) regulation
- On the other hand, if there *are* carers’ regulations, then this is a threat to small and medium sized businesses
- No mention of a redeployment of resources from acute to community care
- Willingness/ability (due to geographical mobility etc.) of younger generation to care for parents to the same extent as the current generation

Scenario three: Choice and division

The following opportunities and challenges were identified for ‘Choice and Division’:

Opportunities

- Direct taxes toward carers
- Develop a needs-led approach towards carers

- Work with and influence employers
- Strengthened role of the voluntary sector in carers' lives
- Enhance and develop the role of carers
- Expansion of technology could lead to better services for carers
- The role of carers becoming more professional and respected
- Carers more involved in decision-making
- Opportunity to develop tax breaks for employers who support carers
- Strong focus on primary care

Challenges

- Health and social work still working in silos
- Danger that choice and assessments become overly complex
- How do we challenge the power of the business community?
- How do we integrate migrant carers?
- Low levels of savings mean that people have less money to purchase care
- The formal role of the NHS has been reduced and diluted, with more resources held by voluntary and private providers
- Voluntary sector becomes over-powerful and mirrors problems of the statutory sector
- Number of hidden carers might grow in this scenario
- Is too much power being concentrated in the hands of GPs?
- Danger of growing rural and urban divide
- The choice agenda appears to restrict opportunities to some recipients of care
- With the reduced role of central government, who co-ordinates and regulates services to carers?
- More work based stress
- High spending, low saving culture prevails
- Delivering choice in rural areas
- What happens to the acute sector in this scenario?
- How can budgets be freed up to support the expansion of choice?
- It is unlikely that a free market of care provision will work in Scotland
- Likely to be a greater divide between middle-class carers – who can purchase good services and use choice to their benefit – over less well-off carers who are stuck with poor services
- Death of building based services such as residential care

- Need to manage the expectations of carers
- Older and healthier population, but there is a lack of quality of life

1.3 Session Three: Setting the course for the future – developing recommendations

In session three the participants were asked to work in the same groups as in session two (i.e. mixed groups with participants from different agencies) and consider how government, public services and unpaid carers could realise the vision for unpaid carers, in light of the distinct opportunities and challenges that each of the scenarios presents. Specifically, participants were asked the question: *What needs to be done now in order to achieve this vision in the future, given the constraints present within the scenario?* The key recommendations and actions raised in relation to each scenario are described below.

What if? Scenario one: prosperity for some

- Means testing to conserve resources to focus provision on poorer carers
- Improved respite provision
- Expansion of direct payments to carers leading to savings in commissioning activity
- Development of powers in community led forums to audit and check quality of service provision to carers
- Expansion of rights to carers giving them the opportunity to decide if they want to care or not
- Promotion of links between carers and further education colleges to provide more training and learning opportunities to carers
- Executive must develop best practice which starts to prepare organisations for trends which are likely to take place over the next 10 years, such as the increase in older people
- Stronger focus in helping carers back into employment through active engagement of employers and training/learning providers
- Build a stronger support amongst employers for helping carers in employment. Work actively to advertise the benefits of having employed carers.
- Review tax benefits system for employers who engage and recruit more carers and develop carer friendly practices
- Extend investors in people programme to include carers' issues
- Extend free transport support schemes to carers, particularly those who are disabled
- Seek an 'alignment of interests' between employers, government and carers
- Involve carers in the development, planning, implementation and monitoring of new carers policies

What if? Scenario two: inflexible cohesion

Actions for carers and carers' organisations

- Continue lobbying on finances
- Promote a stronger angle on rights to choose and refuse caring responsibilities/carers – entitlement in law not to be discriminated against because one is a carer
- Engage and be involved in debate about shaping new organisational boundaries – be involved from the outset in corporate planning – ensure that the needs of carers, and in particular young and BME carers, are built into service design
- Be involved in designing good practice frameworks
- Engage in debate about the role of IT vis-à-vis caring – what we want it to achieve
- Carers funds should not be controlled by local authorities, but should be directly accessible to agencies representing carers
- Either help to enhance the role of carers' advocates, or help to create a new advocacy service (like PALS in England)

Actions for government and the statutory sector

- Tax breaks for employers who provide substantial assistance to carers – more comparable to pattern for pensions, income tax, other benefits
- Flexible working patterns
- Training for staff (e.g. hospital staff on safe lifting) should be made accessible to carers
- Vouchers for carers/carees leaving hospital rather than just information packs
- Consistency and clarity around outcomes – a common language
- Deregulation of immigration – to allow immigrants to support carers (rather than the cared for person) – possibly for their first six months in the country, while they learn English etc.?

Actions for other (non-statutory) organisations

- Anti-discrimination legislation to prevent discrimination in employment because of caring responsibilities
- Support for smaller employers – advice and guidance on how to accommodate the needs of carers
- Voluntary sector needs to look at how to build capacity and engage users better – simpler, more effective methods of engagement, use IT better to do this
- How to overcome the ethos that the only experts are the professionals – attitudinal change needed – big change management agenda
- Encourage employers to promote volunteering – the 'problem' has to be sold to organisations outside of the current caring partnership

What if? Scenario three: choice and division

The overarching goal of government and public services in this scenario is to redress the imbalance between the service providers and the carers, giving more power and control to carers over their own lives. The actions that participants thought would help achieve this include:

- Increased resources for carers. Given the likelihood that resources will be limited, it might be necessary to establish a system of resource allocation that better reflects the needs of different groups of carers.
- Implementation of the Carers Information Strategy, giving carers access to better information
- Increased involvement of carers in community forums and other forms of decision-making.
- Improved monitoring of local agencies' delivery of services to carers to improve the quality of services
- Creation of a set of minimum standards for carers services
- Better support and advice to carers to ensure that they are empowered to influence decision making more effectively
- The development of diverse pathways to enable carers to influence decision making
- Place the carer at the centre of the development, implementation and evaluation of support and services for carers
- Political impetus at the local level can greatly improve local circumstances for carers. More needs to be done to identify local politicians who will champion carers' needs and sustain their role over time.

1.4 Session Four: Identification of robust actions

Robust actions in the context of scenario planning are those actions or recommendations which, if taken forward, will prevail in all of the scenarios and not just one or two of them. The aim of session four, facilitated by Greg Parston from OPM, was to elicit feedback from the workshops dealing with each of the three scenarios and try to identify actions which arose in each of the scenarios, thus creating the robust actions set out in the introduction to this report.

2. Section Two: summary and conclusions

In essence, the event reported here was designed to validate a positive vision for unpaid carers, build consensus, and identify actions where there is uncertainty.

We have provided a full account of the methodology and the tools used to generate the scenarios, with the intention that these can be used again for the unpaid carers policy agenda. The scenarios are tools for planning which could be reutilised or modified for use at a local level (e.g. for a whole systems workshop on reinvigorating carers' strategies). At a national level, the panel of participants (or the Stakeholder Steering Group) could be retained as a 'hub' of dissemination and implementation activity, continuing to meet regularly in order to coordinate and/or catalyse follow-up actions on the 'robust actions' they collaborated to produce.

We hope that, along with the scenarios themselves, these findings and commentaries will contribute to others' thinking about how to prepare for the future.

Annex A: The emerging vision

A vision for unpaid carers in Scotland in 2014

This paper has been developed for attendees at the final meeting of the Care 21 Stakeholder Steering Group for the Future of Unpaid Care in Scotland, on 26 August 2005. It places carers' issues in the UK and Scottish policy context and presents the project's emerging vision for the year 2014. The emerging vision is underpinned by a set of core principles and informed by the research findings from the project, the development of which will form the framework for the final recommendations.

The story so far

The policy dimension

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 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 highlights the vital contribution made by informal carers and sets out a national commitment to supporting carers, bringing carers and carers groups into the policy process locally and nationally, and to 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 for staff in local authorities, social services and the NHS.

As a direct result of the Strategy several significant legislative developments exist within Scotland. The Community Care and Health (Scotland) Act 2002 represents one of several milestones in ensuring that carers are adequately recognised and supported by local authorities and 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 service resources and it cements the centrality of the role of informal 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 Carers Strategy, and standardised the approach nationwide. This re-conceptualisation of carers has to date not been mirrored elsewhere in the UK.

The 2002 Act and subsequent guidance continued to develop the definition of carers to underpin carers' right to a formal assessment of their support needs as care providers. However it also sought to promote early intervention as a means of preventing future breakdown 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 dependant, which may well have a significant impact on the relationship between low income, poor health, institutional support and the ability to care.

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 carers 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 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 assisting them to provide effective care in the community. Ensuring the NHS commitment to carers is delivered will be a key task for the Executive.

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.

In Scotland, there is also a concerted drive to deliver more integrated health and social care. The 'Joint Futures Group', a well-developed policy network that encompasses a range of governmental and non-governmental bodies is helping to 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 integrated care assessments and integrated services as well as quicker and faster decision making and service provision.

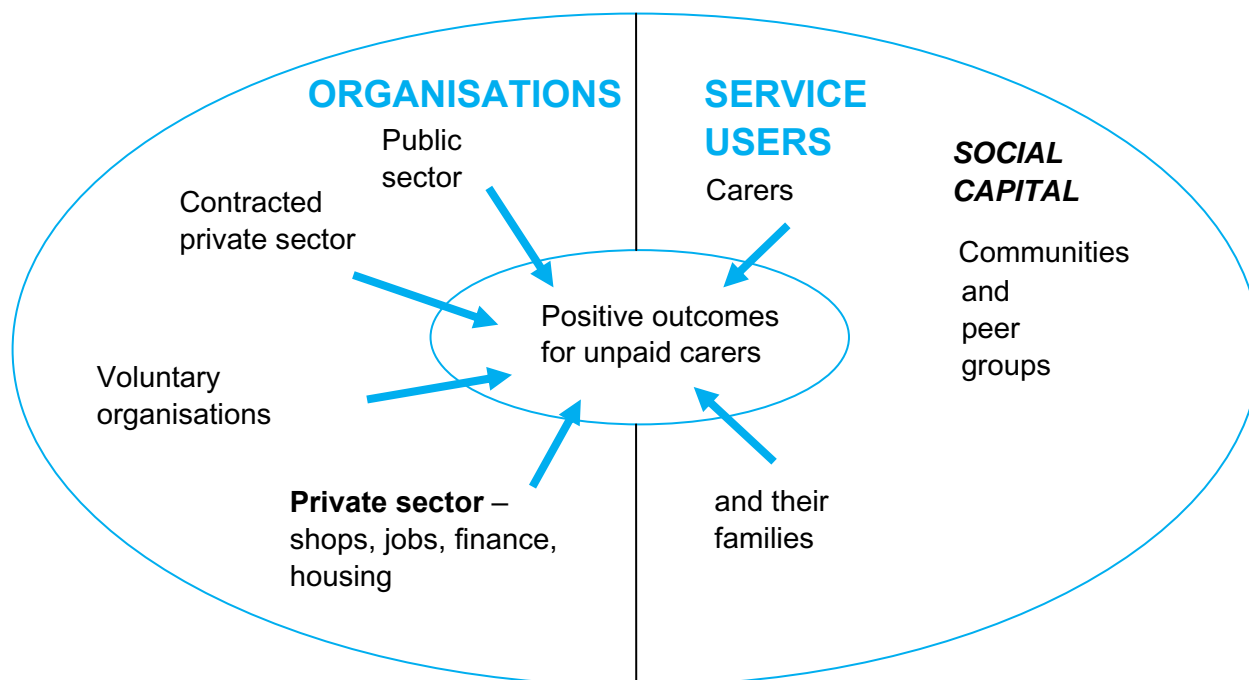
The creation of Care 21, a programme established by the Scottish Executive to drive innovation and change within the social services sector, helps to illustrate the thriving policy context within Scotland. Care 21 consists of a small team appointed by the Executive who will work with all interested parties including; local authorities, the NHS, the regulators and the private and voluntary sectors. The aim of the programme is to create innovative solutions to social care issues through futures exercises, widespread consultation and the identification and dissemination of good practice. In a clear signal of the high profile given in Scotland to the carers' agenda, the first project of the Care 21 Unit was this piece of work on the future of unpaid care.

Links with developing UK policy

The Adult Social Care Green Paper 'Independence, Well-being and Choice' anticipates greater personalisation and choice for service users, but falls short of fully recognising carers as key individual care providers and the UK's largest care force. Many might argue that the vision for building greater capacity for adult social care (on a cost neutral basis) will not be possible without adequate recognition of unpaid carers as knowledgeable, experienced and highly flexible care providers. The Green Paper appears to perpetuate a perception of carers as another client group with demands for 'services' (rather than provider group).

The Health and Social Care White Paper due later this year may well pick up where the consultation around the Adult Social Care Green Paper left off. 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 unpaid carers.

Figure One: Co-production and positive outcomes for unpaid carers



Source: OPM

In Scotland, the recognition granted carers as partners and providers of care in the Community Care and Health (Scotland) Act 2002, means that Scotland is well placed to make gains on the Green Paper's key messages. Also, recognising carers' need for adequate resources to fulfil their caring responsibilities, rather than a need for services in their own right, remains a point of difference from UK-wide policy. 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 are far more integrated in Scottish social policy.

The emerging vision

The under noted summarises the key themes and issues which should be considered with attention to the core principle of **Recognition of Carers as Partners and Key Providers of Care**.

This principle includes

- *recognition* that families and unpaid carers constitute Scotland's largest care force
- the need to harness the contribution of unpaid carers for future care provision, and
- the need to make caring a more positive life-choice.

The principles of strengthening independent living and self-care, and improving quality of life and the quality of care, are also at the heart of this futures study.

1. General messages

Occupationalisation

Emphasis on the 'occupationalisation' of unpaid caring. This differs from a 'professionalisation' of the caring role – few unpaid carers wish to become 'professionals' regulated by standards and contractual obligations – but carers expect recognition of 'occupational' hazards and support to gain occupational skills associated with the caring task.

Where unpaid care has become a significant 'occupation' for an individual, training and support are required. Training of carers should therefore be viewed in a similar manner as training provided to the paid workforce to enable them to fulfil their role.

Choice

This is a consistent theme emerging throughout the study. Carers strongly request that they and the cared for person have more information and choice about the support available to them. They also request greater control over the solutions created to address their support needs. This theme is in line with the concept of 'Personalisation through Participation' being explored by Care 21 for the purposes of the 21st Century Social Work Review.

2. Life-planning

Emerging vision

By 2014, there will be a shift from crisis intervention to planned, preventative support.

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.

This is further evidenced by the voices of carers. Carers seek a shift from 'traditional' assessment (associated with the gate keeping of resources) to 'person centred' planning partnerships (providing the cared for and carer with more control over the services developed and delivered to them).

This does not diminish the role of the professional but redresses the perceived power differential highlighted by many in the study. It also further shifts emphasis of support from crisis intervention to better management of critical stages in caring.

3. Joint working and service development

Emerging vision

By 2014, unpaid carers will be better integrated in joint planning of care and service developments, and in local and national partnerships

The study suggests that carers acknowledge the need and value of professionals but they often criticise their role as assessors and gatekeepers to services. Carers do not yet feel like integrated partners in joint working between professionals, particularly at an individual level. The concept of carers as partners and providers also requires further integration of carers and their representative organisations with statutory partners, as is envisaged for CHP developments.

Carers positively perceive the role of the voluntary sector in providing a wide range of support and the ability to respond flexibly to changing needs. Likely recommendations will seek to harness the concept of co-production of services between carers and professionals, and the capacity of the voluntary sector to support this.

4. Community development and local partnerships

Emerging vision

By 2014, unpaid carers will be able to access a range of support provided by local community initiatives

Supportive local communities can enhance 'self-care confidence'. Well supported community infra-structures and local care economies will enhance choice and local solutions.

Demographic change indicates the growth of the elderly population with potential support needs, but also highlights a growing number of retired people with energies and skills to contribute to community developments. Unlocking this potential within local communities to contribute to the development of flexible support services is highly desirable. Recommendations will seek to harness better partnership working, volunteering and capacity building for community support.

5. Carers' health and well-being

Emerging vision

By 2014, unpaid carers will enjoy good general health and well-being.

The health needs of carers have already been recognised in Professor David Kerr's Report on the future of the NHS in Scotland (cf. Chapter 5: Self-care, carers, volunteering and the voluntary sector: towards a more collaborative approach). The report makes five key 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
- Build 'carer awareness' into professional training.

Care 21 contributed to the preparation of these recommendations, and it is anticipated that the final report will reinforce these recommendations.

The impact of ill-health associated with the unpaid care task is emerging from the study particularly in the physical strain of moving and handling patients, and the emotional impact of caring and social isolation.

Recommendations in the final report are also expected to address the following areas:

- Increased access to counselling and emotional support
- Occupational health provision to match that of paid care staff
- Enhancement of carer-focus in GP contracts
- Closer partnerships between NHS, local authorities and voluntary sector, including reinforcing the aspirations of community health partnerships
- Roll-out of best practice to form national standards and become systematised across Scotland.

6. Resources and financial support

Emerging 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.

It is becoming clear that in order to meet demographic change, carer expectation and to increase the 'attractiveness' of the caring role, finance and resource provision should be considered at individual, local government, Scottish Executive, and Westminster levels.

At an **individual level** carers want to see a more simplified financial welfare system. Carers also expect benefits advice to be broadened into 'financial planning' which enables existing carers to make sound financial decisions, and potential carers to take positive steps of planning the financial impact of care.

Many 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; therefore long-term financial planning is essential.

At **local level**, early findings suggest a strong continuing commitment to public sector provision. However, there is clear demand for a shift in how resources are deployed to ensure that funding more closely follows the carer and cared for person within the overall framework of public services.

This is demonstrated by a clear request to extend the use of Direct Payments to pay carers who may live in the same household. This is already standard practice in other countries (eg Germany, Netherlands, Austria, and Sweden)

Carers also want to see greater accountability of local authority and NHS spending on care and respite, and a shift in control over resources as a way of making services more responsive.

Carers understand resource constraints, but increasingly expect a stronger voice in service planning, greater accountability, and demonstrated outcomes from public service provision.

At **national level**, the exercise indicates that carers increasingly expect government to create new revenue streams to underpin a growth of care services and quality. Carers also request direct measures to support carers as partner providers rather than through 'benefits' (eg. carer income irrespective of age, pension credits for carers forced to reduce employment).

It has been noted throughout the course of the exercise that respondents can't envisage how an increased volume of service requirements can be supported if taxation or national insurance payments don't rise substantially. Stakeholders are sympathetic to the use of taxation levers to improve care support, but do not feel adequately equipped to recommend specific models from other countries.

Some suggestions are emerging that caring could be encouraged through enhanced tax and national insurance thresholds, or through exemptions, to attract people on benefit support, in part-time employment, or retired people willing to take up a caring role in their communities. Measures which contribute to the development of more sustainable and caring communities could therefore help to create a more flexible paid careforce and ease the recruitment of domiciliary staff.

This exercise may produce recommendations to initiate a national debate on the future funding of care in Scotland and the role of taxation.

7. Training and education

Emerging vision

By 2014:

- Carers will be able to access training at different stages of their caring journey
- Carers will be supported in their work–care balance, and training is provided should they choose to return to work
- All professional training will contain carer modules and input from carers and service users, and
- Volunteer training will be available to develop care support.

In line with the 'occupationalisation' of the 'unpaid careforce' it is emerging that training for carers is required to assist with their care tasks.

As detailed above, the Kerr Report proposes to develop 'Expert Carer' training programmes. Such training programmes will achieve the long-term objectives of partnership, recognition of carers as key providers and increase the quality of care provision to those who need it. The Care 21 final report is expected to confirm these recommendations.

8. Practical support

Emerging vision

By 2014, carers will be entitled to regular breaks from caring and have ready access to local practical support.

Regular breaks from caring and high quality 'tailored' respite continue to feature highly on the carer agenda. Such provision remains patchy across Scotland and carers often cite the difficulty in accessing appropriate respite through health and social care agencies.

The report is likely to include recommendations to establish a national strategic framework for the development of short breaks and breaks from caring.

Access to aids and adaptations is also emerging as a key issue for carers. By 2014 it is carers request that aids and adaptations should be more accessible and visible 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.

9. Specific groups

9.1 Young carers

Emerging vision

Young carers are supported in their development as children in a family setting. Families benefit from comprehensive services which minimise the impact of caring responsibilities on young people.

Key messages for Young Carer support include:

- recognition of young carers as vulnerable young people, not partners and providers of care.
- 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 which can offer young carers peer support, breaks from living and caring routines, and person-centred learning and development support.

The distinct situation of young carers and the complexities of partnerships required suggest the need for a national framework for development which has already been endorsed by Ministers and will be reinforced in recommendations of the report.

9.2 Black and minority ethnic carers

Emerging vision

Care agencies 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

While the experience of 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 groups. There are some specific conditions which are more prevalent in certain communities. Support services which are effective for many groups are inappropriate for others (e.g. some forms of respite) and so

workforce development must enable a critical reflection on 'Eurocentric' models of care and support if carers from BME groups are to be better enabled as partners in the future.

9.3 Carers with mental health issues or learning disability

Emerging vision

By 2014, carers who themselves have mental health issues or learning difficulties will feel as valued and supported as competent, capable partners in care.

By 2014, carers with mental health issues or learning difficulties will cite less the stigma often attached with mental illness as a complicating factor to accessing services. They will be enabled by a range of agencies who offer mostly practical support to communicate needs and challenge assumptions about the capabilities of these groups.

For carers who face particular difficulties expressing their needs poor co-ordination of services are made more acute. In particular, carers with mental health issues experience difficulty negotiating access to respite, and navigating their way through what is perceived to be a complex web of interrelated benefits entitlements.

In many cases, carers with learning disabilities and mental health issues need close personal and practical 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.

Annex B: The scenarios (full narratives)

Scenario 1. Prosperity for some

In 2015 Scotland has a labour/liberal democrat coalition administration, although the political philosophy guiding policy making has altered markedly since 2005. The guiding philosophy driving policy has changed from one which largely saw the state, and public services, as the driver of social improvement, to one where this role is taken by individuals and communities – harking back to the policies which drove the Conservative Government in the early 1990s. Some of this change of emphasis has been the necessary result of political expediency – the Conservative Government in England has sought to reduce the burden of taxation and public spending, at the same time as rallying its English MPs and supporters by cutting spending on Scotland. The Barnett Formula, which for generations had given Scotland a larger percentage share of public spending over England, was reformed in 2010 giving Scotland a much lower cut of public spending. The other reason for the change of emphasis has been the growing belief in intellectual circles in Scotland, and amongst the middle classes, that the burgeoning public sector – controlled vigorously from the Centre – was no longer appropriate to a Scotland increasingly competing in a globalised economy.

The population changes in Scotland over the past 30 years are continuing to cause concern. The Scottish population is both ageing and shrinking. In 2009 the population of people over 65 exceeded the population of people under 16 for the first time, driven both by reducing birth rates, higher life expectancy, and continued outward migration. The Scottish population that peaked at almost five and a quarter million in the 1970s has dropped below the five-million level for the first time and is expected to continue shrinking. In 2015, Scotland is the only country in Europe with a shrinking population and the problem is expected to worsen with the number of over 65s expected to be double the number of under 16s within the next 20 years.

Economy

In 2014 the economy grew by 2%, well above the rate for most successful countries in Europe, and is expected to grow by 1.8% this year, but this is largely due to the success of the financial sector. While the industrial sectors in Scotland have continued to decline for the last decade, employing fewer people, this has been more than offset by the growth in the financial sectors, tourism, retail and the high technology industries and support providers. The financial sector, as one of the main sections of the economy, has seen the most rapid growth, with Edinburgh in particular, continuing to grow its financial services sector, becoming one of the major locations for finance in Europe.

The economic focus of the Westminster government has been on liberalisation. They have reduced business rates, lowered the top rate of taxation and withdrawn the UK from some of the more onerous European regulations, such as the Working Time Directive. The economy is built on knowledge, skills, and an ability to attract capital investment from around the world. Unfortunately, to meet the rigours of global capitalism, this has meant that a growing numbers of countries have outsourced parts of their businesses, particularly ICT support and call centres, to low wage countries such as India, while manufacturing has continued to deteriorate. Scotland has suffered as a result of both of these trends. The traditional manufacturing areas, particularly Glasgow, have suffered greatly. By contrast, Edinburgh has been able both to consolidate its reputation as an international financial centre – continuing to host a number of head quarters for banks and insurance firms – while attracting new companies to its business development areas in reclaimed land in Leith docks and in the new business corridor that connects Edinburgh's huge international airport and the city centre. These shifts have merely served to heighten regional differences within the country and have left the administration facing the difficult task of trying to translate regional strength into national success.

With the workforce ageing, Scotland is struggling to develop enough skilled workers to enter key vacancies. At first the administration sought to attract immigrants, but after the arrival of the Conservative Government, and increased fears over terrorists, there has been an almost complete clampdown on the number of immigrants entering UK, making it difficult – given the UK government's control over immigration policy – for Scotland to attract more than a few thousand new workers a year.

The population imbalance that is developing has seen the proportion of workers over the age of 30 growing steadily and will soon reach a point whereby the majority of those in the labour force are over the age of 45. This makes older workers the mainstay of the economy. As a consequence older workers in Scotland have to work longer hours than ever before, and in order to respond to rapidly changing employment markets, be willing to change jobs much more often in their careers. It is not unheard of in Scotland in 2015 for professionals to change jobs three times in the space of 5 years, jumping from one profession to a completely different one several times. Scots also work later into their lives, with many now choosing to work into their 70s. The UK Government's decision to extend the retirement age to 75 means that many now feel obliged to work until this age and beyond.

Targeting what they see as the high levels of reliance on benefits in some sectors, the Government in Westminster has sought to further restrict people's abilities to rely on the state for help. The main change has been the removal of incapacity and disabilities benefit, to be replaced by the 'help up' benefit, which is both heavily means-tested – making it available to only the most deprived – and time-limited – with recipients given the benefit for only 3 months before they have to go through a rigorous testing for an extension.

Public services

The latest spending round, like the one before, announced a further reduction in government spending on public services. From the peak in 2008, public spending has fallen year on year. This has led to decreases both in core funding for public services – down 2% of GDP since 1996 – and on the number of public servants, especially in central government roles. The McMillan Commission – Established in 2008 to oversee massive 'efficiency savings in Scottish Government', has now been rolled out, leading to the loss of 3,000 jobs in the Scottish Executive and other non departmental agencies. The NHS and local government have started to follow suit, axing several thousand management, administrative, policy and strategic planning positions.

Although initially resisted by public sector unions, reductions in public spending have led to swingeing cuts in public service jobs, particularly in terms of administrative and management positions. In the area of social care, for example, it is not unknown for local authorities to have lost 20% of their managers, administrators and project managers over the last four years, with devastating consequences on the ability of social care providers to provide non essential social care services, such as respite, non urgent home visits, and day care.

Statutory social care is increasingly restricted to those with the greatest needs, which has meant there is an increasing lack of effective provision for those with lower level needs to allow them to live independently. As a result, more people with lower needs are looking for help from friends, relatives and the voluntary sector.

For at least the last four years, reform of public services has been underpinned by three themes: shift of resources to the front line, decentralisation to localities, and freedom to choose. Each of these policy themes has had a massive impact on the way in which public services are organised and delivered. The first two themes go hand in hand. Shifting resources to the front line is a policy which focuses on giving more say to front-line workers such as doctors, teachers and nurses, at the same time as reducing the decision-making powers of public service 'managers.' The result thus far, has been the dramatic reduction in the number of public managers in the NHS, Local Housing, Education, Housing and Social Work departments. Where savings have emerged, more money has been directed towards the recruitment of front-line workers such as doctors, nurses, care workers and teachers.

The second theme, decentralisation, ties in directly to the first theme. In this case, the policy is about giving local people, including front-line workers, more say over service planning and resource allocation decisions. Within all local authorities, new Community Asset Bodies (CABs) have been established, which comprise a range of local people, including carers, public service professionals and elected members, with sweeping powers to make decisions over local resource allocations, service planning decisions and the setting of local targets. At the same time, National Inspection and Auditing Bodies, greatly reduced in size thanks to McMillan, have fewer powers to set performance indicators or intervene where providers are failing. There are 30% fewer government centrally selected targets than there were in 2005. At the same time, CABs have the power to intervene where they deem a local service has failed, either calling in interim management teams to take control of failing organisations or choosing to run organisations themselves, which the administration gives them both logistical support and resources to do.

There are strongly polarised views on the relative success of these changes to policy. On the centre right of politics, commentators argue that the three-pronged focus on devolution, choice and the front line has importantly given local people and front line workers a greater say in the development of local services, while restricting the power of central government to impose priorities and targets which might not reflect local needs. On the left and centre, many charge that the changes have increased variability of performance in different areas and led to a lack of service planning and continuity.

The setting up of CABs has proven a particularly divisive area of policy: provoking consternation amongst those who respect traditional modes of public service delivery and joy amongst the centre right who seek radical change. Traditionalists want to see greater probity and accountability held at a national level to promote the equitable delivery of services. They point to recent evidence towards a polarisation of performance between the best and worst public services. Those on the centre right of politics, however, believe CABs have re-invigorated local politics, ensured that local priorities better meet local need, and strengthened the voice of the voluntary and community sectors.

Freedom to choose, the third theme, focuses on widening the range of choices available to citizens when they access public services. Once restricted to choosing which hospital they are treated in – the outcome of the choice agenda promoted by the previous Labour/Liberal Democrat coalition, service users can now choose which GP or consultant they see. In addition, in a marked departure from the cautious choice reforms of previous administrations, they can also choose from a menu of local providers whether to be treated in the private, voluntary or public sector.

The government, has, however, struggled to pay for choice. Faced with a lack of capacity to offer real choice and the lack of funds to pay for increased capacity, it has sought to increase the revenue through a new range of charges. While those on very low incomes, or eligible for benefits, are excluded, most patients now have to pay a range of new charges for some NHS services, including charges for moving to a better room – the new 'NHS upgrade tariff' – to see their GP, and to receive physiotherapy.

The belief that the community can be a major driver for social improvement underpins much of the government rhetoric and policy in regards to public service reform. Specifically, the government sees the voluntary sector, supported by voluntary activity, as central to promoting self-reliant, strong and cohesive communities. In order to boost community activity, particularly in deprived communities, the Government recently established 'social capital grants' which can be used by local authorities, in partnership with CABs, to support local community volunteering activities, such as volunteering to improve the environment, care for older people, and provide learning opportunities.

Health and social care

In 2015, Scotland continues to hold the record as one of the least healthy countries in the industrialised world. This does not mean there have not been some important advances to the nation's health; premature deaths as a result of cancers, strokes and coronary heart disease have decreased markedly over the last 10 years – but trends have not kept up with advancements in

other countries. There has also been some success in tackling Scotland's dependence on alcohol and smoking, with a reduction in the number of illnesses relating to both.

At the same time, however, health inequalities have grown. The gap between health outcomes in the most deprived and least deprived communities are now wider than ever. While the life expectancies of all groups has increased – a trend reflected in the overall demographic data in Scotland – there is evidence of a growing number of older people with chronic conditions such as diabetes, dementia, arthritis and severe mobility problems. These trends, along with advances in medical technology, have meant that more people are living with complex conditions and are doing so for greater lengths of time than ever before. The interplay of these trends in health has led to an increase in the overall number of people with disabilities and an increase in the numbers economically inactive due to limiting long-term illness.

Carers

There has been a steady increase in the number of people undertaking caring responsibilities. There are three main reasons for the rise:

- The increase in the number of older people living longer, many of whom require significant support with their care
- The growing numbers of people with chronic diseases and complex care needs,
- And the reduction in the ability of the traditional providers of social care, particularly local authorities and the NHS, to provide services to both those who need care, and those who provide.

The likelihood of becoming a carer in 2015 is sharply influenced by socio-economic circumstances. In the last 10 years, the number of carers from working class backgrounds has increased at twice the rate of those from middle class backgrounds. More economically prosperous than ever before, and the main beneficiaries of the economic boom, middle class Scots have been better able to 'buy' their way out of caring responsibilities, increasingly purchasing care support from the private sector. The private residential care home sector, increasingly able to offer a higher quality of service than the public sector, has been a key beneficiary of this growing purchasing power. Those living in more deprived circumstances, or on lower wages, have experiencing declining levels of care provided through the public sector. Forced to rely on cash strapped social care providers and overcrowded care homes, this segment of society has had to take on a growing amount of caring responsibility.

The demand for support for those who receive and provide care looks set to continue to grow, even in the face of public service funding cuts. This dichotomy has placed public services under ever growing pressure. On the one hand, given more money to increase the role of the front-line – through the recruitment of more doctors, health care workers and nurses – public services have in some cases been able to improve primary care services. The number of people waiting to see their GP has fallen to the lowest levels recorded in over 20 years. On the other hand, the reductions in overall funding has led many public services to cut back on less urgent or more periphery services. On the list of services facing cuts have been community and adult education, leisure and library services, cultural and sport services, and community centre provision.

Jean Smith from South Lanarkshire, who cares full time for a disabled adult son, laments the cuts in local community services. She told us:

'The careers centre is not doing enough to help him...he needs help to boost his confidence which will help him go out and get a job. He is too embarrassed to go and ask for help. He has problems with literacy but will not ask for support. He sees support as stigmatised and will not accept help.'

There has, however, been a growing role for the voluntary sector in providing services to both carers and the cared for. The government, keen to foster a culture of 'self-supporting communities' has increased the level of direct and grant funding to voluntary agencies, giving them a role to lead the development of services in areas formally delivered by public services, including services to carers.

Living in the new 'urban village' in West Lothian, Andy Falconer, who cares for his wife said:

'The support group is excellent and probably my biggest source of support. I can discuss my experiences with other carers who understand my situation. The only draw back is I cannot always make the support group because of my caring responsibilities.'

By their nature such voluntary and community services rely upon people in the local area to provide the service. As a consequence the coverage is sporadic and more assistance tends to be available in affluent areas than in poorer areas. The nature of the services offered varies greatly from group to group and there are many areas in which certain types of assistance aren't available at all.

A recent study by Edinburgh university revealed that nationally young carers were 45% less likely to leave school with a formal qualification than their peers, and that this figure rose to 55% for BME young carers.

Despite a merger between two of the UK's larger carer organisations (and mirrored in Scotland) the voice of carers is not heard loudly in Westminster or Holyrood. Promises made by a series of portfolio holders remain aspirational, and this is not helped by the high turnover of ministers with responsibility for community care and carers issues. Despite a push on direct payments and carers, assessments the number of carers supported to take up 'cash for services' stagnated after an early and promising rise.

A developing performance management system for social work departments, informed by the 21st Century review of social work, has generally failed to have the impact that many expected. Many departments cited the reduction in local authorities from 32 to eight as a major contributory factor to staff turnover and service disruption.

Service integration between health and social care has largely left carers behind, and many still cite 'border disputes' amongst professionals as a tiresome frustration. Carers' organisations in the community and voluntary sector still cite short-term (e.g. 1-2 year) service level agreements as a major impediment to fuller partnership status, and are largely excluded from representing the voices of carers in local planning forums, in all but a few areas where they have begun to act more aggressively toward statutory commissioners and collaborate with each other.

Despite carers' health becoming a major public health issue there has been little movement in the health and social dis-benefits of caring, as reported by carers. The balance of care still falls predominantly on working age women in lower socio-economic groups. New GP contracts have brought a greater focus to carers' health issues as GPs are more closely incentivised to monitor the health of high intensity carers (50 hours plus per week) in their area. The recent murder-suicide of an unemployed middle aged man with mental health problems caring for his elderly mother in Dundee was the subject of an inquiry, after it was found that his repeated attempts to move closer to her had been thwarted by delays in the Housing Department, and his requests for respite and assistance from the benefits service to help manage his spiralling debt had driven him to despair.

The consistent message that every recent carers' survey has expressed is the ongoing frustration that carers feel that 'government knows best' and that 'only the well off are able to improve their quality of life'. This is further reflected in 2011 Census figures which show that there has been an increase in the number of high intensity carers and that these are over-represented at lower socio-economic groups.

Society and lifestyles

The structure of Scottish society continues to change. The number of marriages in Scotland, which briefly increased between 2006 and 2010, has started to decline again. More Scottish adults report living on their own, and in the case of women, not having children. Observation of religion in all communities, but particularly amongst younger groups, continues to decline. Although party political

affiliation has declined, participation in political activity – and in green and environmental politics in particular has increased.

Attitudes towards society continue to be mixed. When surveyed last year, 25% of Scots between the ages of 15 and 45 reported that there was 'no such thing as society.' This finding may be associated with the finding that an increasing number of people from all age groups felt more isolated and lonely. However, in a finding that confounded pollsters, more people than previously polled, and a growing number over the last 10 years, said that it is important for people to help those less fortunate than themselves. The survey also found that more people acknowledged the needs of carers, largely because of the increasing number of people that had become carers or had known someone who had done so.

The gap between the rich and the poor has widened and the overall levels of poverty have increased. The situation has created some deep fault lines within Scotland. On the one hand, there has been a small increase in the number of people joining the middle class, a factor helped by the reduction in income tax for low earners, while on the other hand there has been an increase in the very poor – living in conditions that have improved little in 10 years. There has also been a growth of those with very high level of incomes, with many people now able to afford million-pound houses and command huge salaries. As well as widening disparities between the rich and the poor, Scotland is also experiencing widening regional disparities. The differences between the East and West continue to grow with Glasgow continuing to suffer from de-industrialisation and high unemployment whilst Edinburgh and the surrounding areas has been able to build itself into a service hub for UK based companies.

Working lives in Scotland have changed significantly over the past decade but have done so in very different ways for different groups. The increasing numbers of people working in the service sector, and particularly those working in service support roles for corporations, are being asked to work longer hours in order to compete with lower cost economies. This involves an increasing amount of evening and weekend work, increased incidences of shift work, and the expectation that workers will be flexible and willing to respond to the needs of the employer. By contrast those working in higher paid roles in financial services and other businesses are increasingly utilising technology to allow them to work from home. This has increased the flexibility of their working lives and allows them to structure their working hours more to their liking.

Annex: Scenario trends

The following graphs are outputs from the economic modelling strand of the Care 21 Future of Unpaid Care research project. An economic modelling tool has been developed by OPM and Experian Business Strategies for the purposes of predicting the likely demand for unpaid care in Scotland over the next decade. The model is based upon core data from the Scottish Household Survey, and has been developed with scenario planning in mind such that assumptions about key variables thought to impact upon unpaid care (age, household tenure/ deprivation, co-habitation, dependents), can be changed.

Figure 1: Population

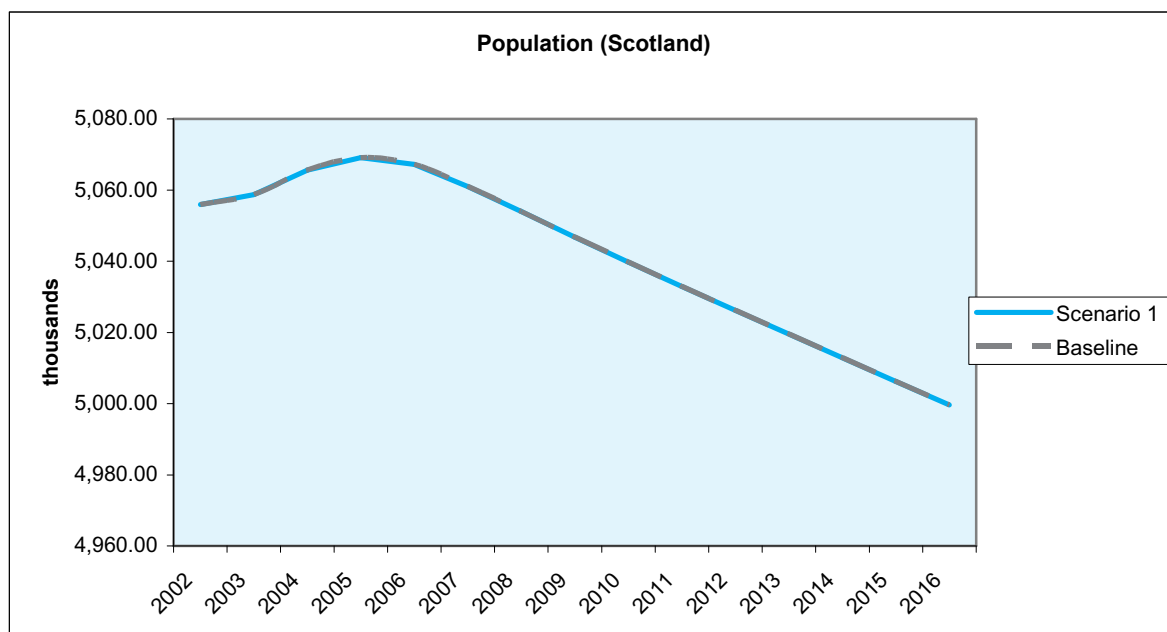


Figure 2: Change in population by age band

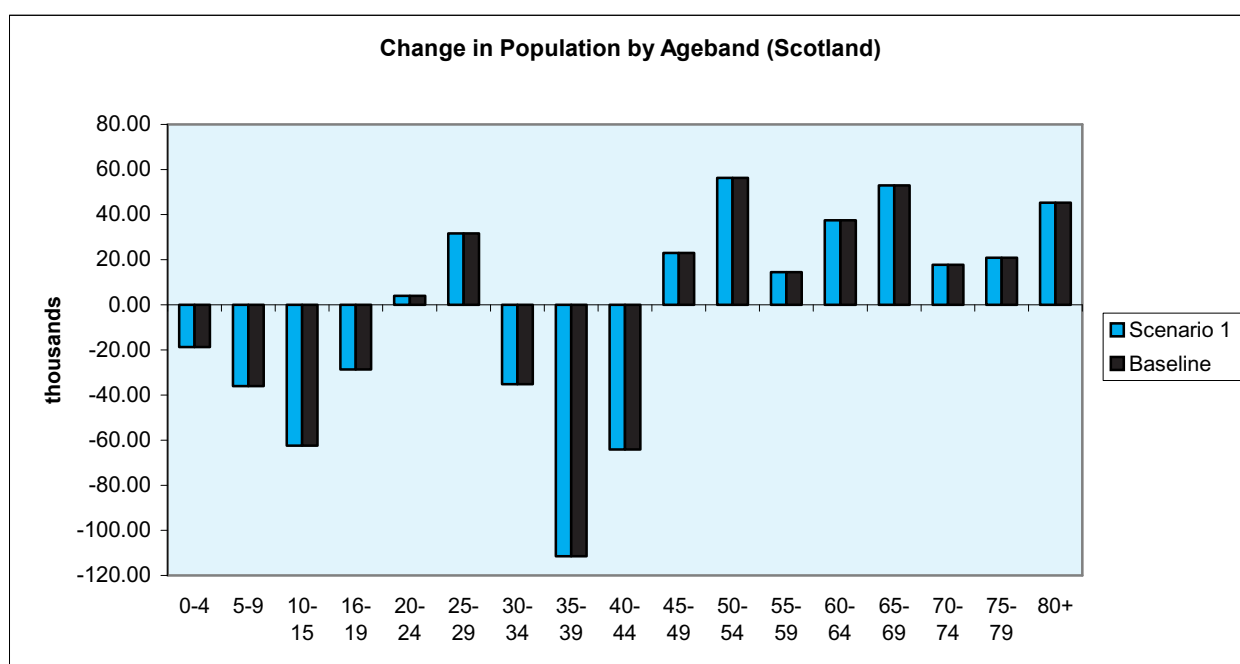


Figure 3: Unpaid care

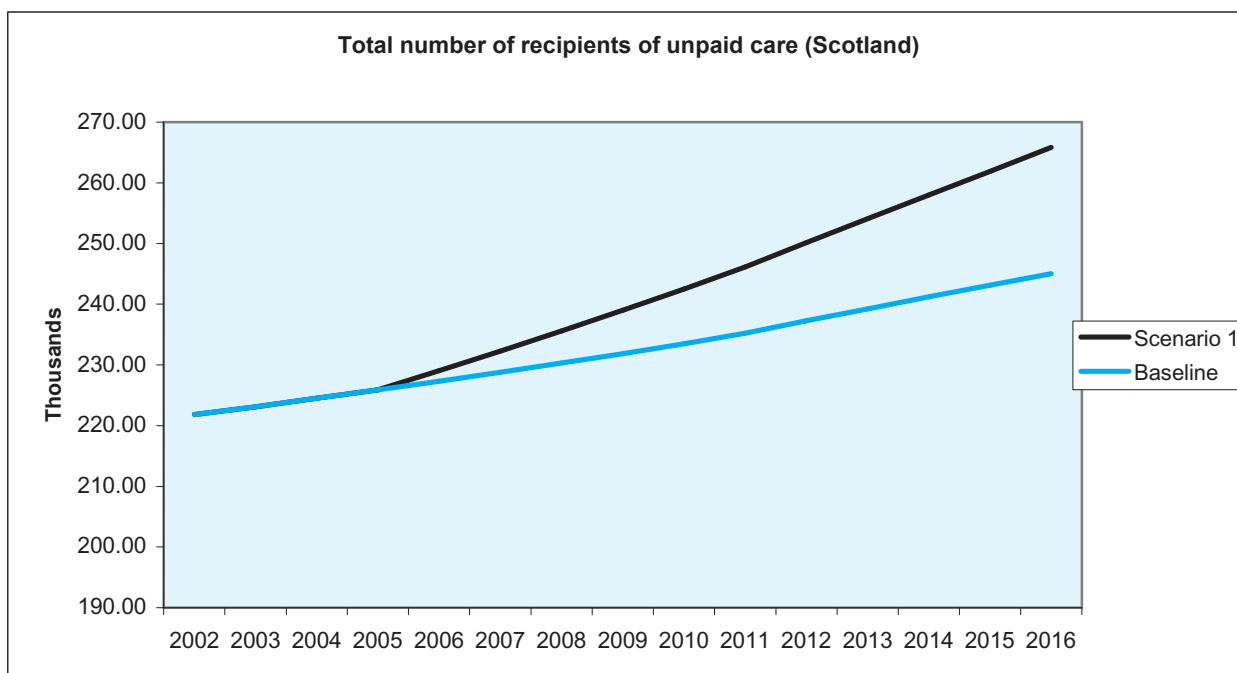


Figure 4: Tenants

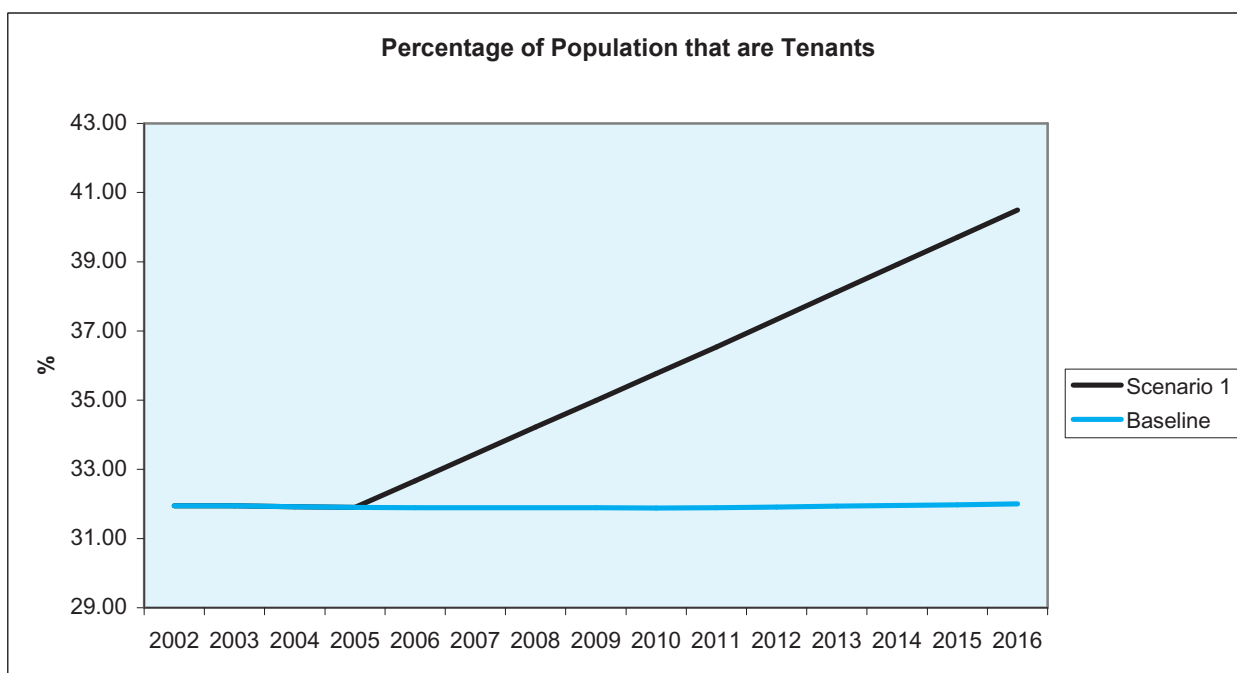


Figure 5: Co-habiting elderly

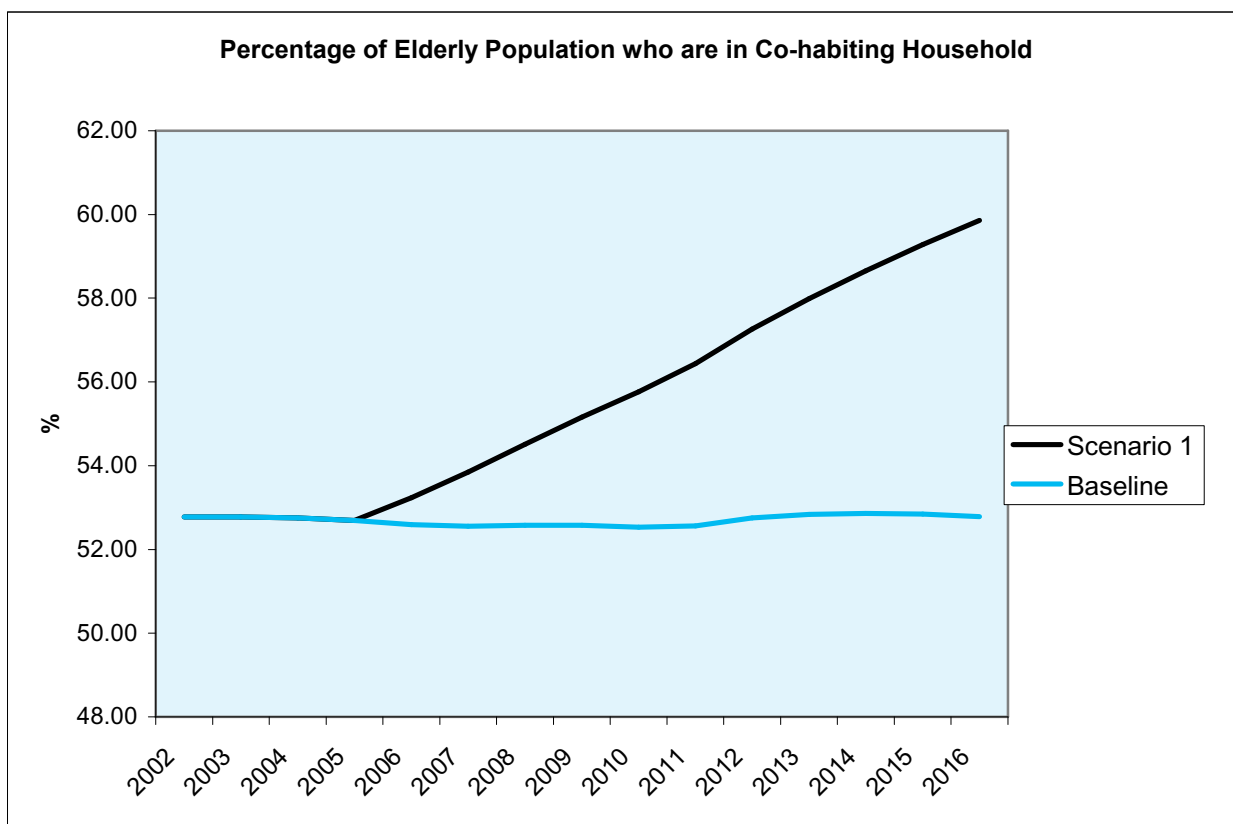
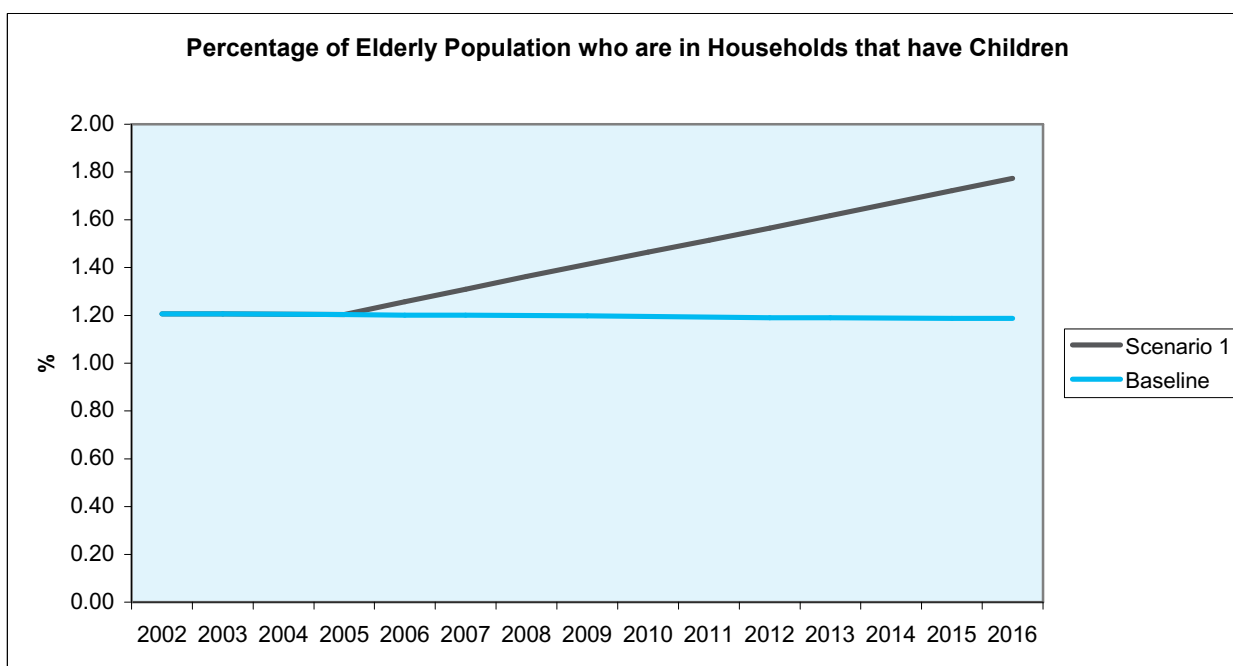


Figure 6: Elderly in households with children



Scenario 2. Inflexible cohesion

The 2012 Scottish elections, although returning a Labour led coalition with the Scottish Socialist Party and the Greens, gave a mandate to a combination of politicians widely viewed to be on the social democratic left of politics in Scotland rather than the 'centre' preferred by the previous administration. Pushed heavily in the election by the SNP, who were presenting a vision of an independent social democratic Scotland, the Labour party has been accused by modernisers of taking the administration to the left. The leader, former academic John Carr, disputes this, calling his administration 'the party of the community.' Since taking power they have sought to bolster public spending, have raised taxation slightly, using the devolved powers for increasing income tax for the first time, and put the community at the heart of government. They have received support from the Labour administration at Westminster, which, after almost 20 years in power, holds only a very narrow majority. They have, as a result, been forced to make concessions to the other parties and so the past few years have seen taxation rises curbed and public spending slow down considerably.

The government has, thus far, bucked the UK trend and kept the state retirement age at 65. They have also greatly increased the size of the public sector workforce and have made significant changes to the provision of care and health services. Entitlement to assistance has been extended and the government has increasingly moved towards the social democratic model of state provision. They have kept Scottish public spending levels above the UK average and as a result the past decade has seen significant improvements to the health of people in Scotland.

Economy and workforce

The UK and Scottish economies have ailed over the past five years because of the higher taxation and wage costs in the UK. The UK, at first a major benefactor from EU expansion – through the low cost labour these countries sent to the UK – have increasingly suffered as a result of these countries' ability to cut costs and attract inward investment. The UK has also suffered from seeing many of its larger companies outsource sections of their businesses to low wage countries like India and Pakistan. Whilst this has particularly hit the manufacturing sector it has also had an impact on the financial and service sectors, the mainstay of the Scottish economy in recent years. These sectors, although still relatively strong, are seen to have suffered because of the declining spending power of Scottish consumers and the growth of internet shopping, which has seen customers able to import goods more cheaply over the net.

The economic downturn has not, however, impacted negatively on all of the areas of the Scottish Economy. Faced with declining employment and subsiding inward investment late in the first decade of the century, Scotland introduced a number of business promotion zones (BPZs), where companies seeking to establish business interests in Scotland were given government subsidies and reduced taxes if they set up in the zones. Linked to Scotland's still renowned universities, the business Zones, established in Edinburgh, Dundee and Glasgow, were successful in attracting several international technological companies, bringing with them skilled labour. Edinburgh, still the economically dominant city in Scotland, has seen a decline in its economic growth. The vanguard of Scotland's economic boom between 2006 and 2009, the city is now seen to have over-reached, investing hugely in housing, infrastructure and business ventures, many of which now lie underused or derelict.

The economy in Scotland has weakened over recent years, growing at only 0.9% of GDP last year, and 0.1% this year. The manufacturing, building and construction sectors have technically been in recession since 2010. The financial sector, based mainly in Edinburgh, has seen a sharp fall in growth, particularly in light of the growth of competing financial centres in Warsaw, Budapest and Prague. The service sector, on the other hand, has continued to record some growth due to the relatively low cost of labour, the higher wages of public sector workers and the growth in take home pay felt by many lower paid workers. In addition, the business promotion zones, and the relatively high education and skills levels in some parts of the Scottish economy have ensured that Scotland has sustained and grown some key knowledge industries.

The EU, which has re-established itself as a major and credible decision making body – boosted by the decision in 2010 from Denmark, Estonia, Poland and Cyprus to enter the single currency, and to let Turkey enter the Union in 2012 – has strengthened European human rights, equalities and employment law, greatly increasing the number of legal obligations imposed on UK employers. According to Lance Davidson, Chair of CBI Scotland, the Scottish workforce is the most ‘inflexible’ it has ever been. The Scottish government has sought to address these changes by dramatically increasing the levels of skills training and provision targeted at the lower ends of the economy and has a stated aim to make ‘every Scot capable of doing every Scottish job.’

In spite of the fact that the natural rate of decline in the Scottish population has continued, the government have been able to stabilise the size of the Scottish economy by attracting immigrants from both the UK and the rest of the world. This has led to a significant growth in black and minority ethnic communities and has brought with it an unexpected rise in the number of under 30s within the population. Skills levels are still an issue both in immigrant and local populations but take-up of training is on the increase.

Public services

Consistently high levels of public spending over the last decade has brought about tangible improvements in public services. This has helped a progressive consensus to build in Scotland which sees high levels of public investment as necessary to the future of the country. Those in favour of the government’s policies point to the lowest levels of crime for three decades, reduced waiting times for hospital treatments, more nurses and doctors than ever, and improved school exam results. They also point to the reduction in the level of poverty in Scotland as a strong reason for keeping the social democratic consensus.

The Scottish administration’s policies are underpinned by two themes: investment met with excellence and building cohesive communities. The first theme of reform posits that public services should only receive increased investment if they can demonstrate improved delivery of public services. Challenged by a report by the Scottish Fiscal Institute, published in 2012, which concluded that Scottish public services were ‘highly inefficient’, the administration has sought to make it a responsibility of public services to deliver more for their money. To drive improvement, the government has introduced a wide range of performance measures, now called Community Investment Measures (CIMs). The auditing regime, which briefly shrunk under the last administration, has increased in size to administer and enforce the new performance management regime. The new Centre for Excellence in Communities now audits performance of all the main public services, including the NHS, local authorities and schools.

The Scottish administration has grown in size over recent years, with the Scottish Executive significantly increasing its capacity, along with other bodies like Communities Scotland – the administration’s favourite organisation. The growth in size is seen as necessary in order to help the administration work with public services to improve the quality of service delivery. In particular, the Executive has increased its role in providing research, promoting good practice, monitoring and challenging performance, and promoting effective service delivery.

In order to focus improvements in areas which are deemed weak, the Executive has made available a whole range of different ringfenced funds to boost performance in these areas. An example of this is the ‘carers community asset fund’ which gives social work departments and the NHS money to invest in improvements to services for carers.

Not all of the administration’s efforts, however, are focused on providing support, funding and policy advice. Where public services are deemed to be failing, new ‘hit squads’ have been established with sweeping powers to enter and take over failing organisations and ensure quick turnarounds in performance. Initially viewed by public service professionals as necessary in light of the poor performance of some local authorities, many now say the interventions have gone too far, creating a ‘culture of fear’ at the top of organisations.

The second theme of reform, building cohesive communities, is focused on building stronger, closer, and more mutually supportive communities. In a recent speech, the First Minister called for individuals to 'work together to build a stronger sense of community, mutual respect, and the infrastructure to support those less fortunate.' To support this agenda, the administration has introduced three main policy changes:

Community Bonds – The new bonds are the centrepiece of the cohesive communities agenda. They are substantial pots of money made available through local authorities to community groups to invest in community related services and infrastructure. Increasingly, they are used by groups of carers to support the development of local care services or to develop day care or new community facilities for carers. They can also purchase services from the voluntary sector, although the private sector is largely excluded from the list of local providers.

'Extended' Community Planning Partnership – The government has handed increased powers and greater resources to community planning partnerships that it now calls 'Extended Community Planning Partnerships.' Legislation has made this mandatory and more prescriptive in terms of pooled and aligned budgets, making it essential for all partners to be at present. Although still dominated by local authorities, community partnerships have become organisations in their own right, undertaking detailed planning, budgeting, consultation and delivery of public services.

Community Teams – Community Teams are at the forefront of driving local community development initiatives. Community Teams, which usually comprise a mixture of volunteers (some unemployed or young people) and those who have retired, are commissioned by local authorities to invest time and resources into local community projects, such as environmental schemes, social care projects, and local building and construction projects. Interviewed recently about the scheme, a policy officer responsible for the scheme in a local authority told us, 'Community Teams hark back to the idea of the New Deal in 1930s America, when the government paid unemployed people to carry out worthy projects – it's a way of building stronger community bonds and giving people something to do.'

At the heart of these initiatives is a shift in the model of leadership and an attempt to bring the end service user or their representative closer to the planning and delivery of services.

Volunteers are seen as an integral part of the driver for stronger communities, with the administration rarely missing an opportunity to propound their virtues. However, most recent commentary and research on volunteering seems to suggest a worrying decline in the numbers of volunteers. The most recent research report by a national volunteering agency, entitled 'What is in it for me?' reported a rising complacency in government and elsewhere in relation to volunteering, with the researchers suggesting that the decline is due to there being an over-reliance on public services to provide the public good. Others point to the failure to attract younger people into volunteering.

Carers

The number of people who undertake caring responsibilities has grown markedly over the last 10 years. The main reason for this increase is the growth in the number of older people who need long-term and intensive care and support. There has also been a small, but growing, number of younger people who need unpaid care. This includes people with learning disabilities, those with severe disabilities, and those with mental ill health, such as depression.

Although people in Scotland are living longer, more older people experience complex care problems, such as diabetes, arthritis and heart difficulties. This group, while well supported for their acute needs by the NHS and social work, require an increasing amount of support from unpaid carers.

The increase in the number of carers appears to cut across social class and ethnic backgrounds. A recent survey of unpaid carers found there to be a 5% increase over the last 10 years in carers from social classes 1, 2 and 3 (professional occupations, managerial and technical occupations, and skilled occupations, respectively). This growth has been explained in terms of there being a steady

increase in the number of more prosperous older people who are living longer but still have complex care needs. While this group may be able to afford some private care – and in more severe cases residential care – these older people still require substantial support from relatives and friends.

There has similarly been an increase, at a slightly faster rate, of carers from deprived backgrounds or lower social classes – 7% according to the same survey. According to researchers, this group is more involved in caring for others because there has been a significant rise in the number of older people with complex care needs. The group being cared for, while living longer than ever, suffer from a range of health problems such as dementia, obesity, diabetes and heart conditions. Unlike the more prosperous older people, this group is almost entirely reliant on local public services and their family and friends for support.

The number of black and minority ethnic carers has also grown. According to recent research, this growth is largely down to the increasing numbers of first and second generation older black and minority ethnic people who now need support and care in their older age. The same research also suggested that there was a stronger tradition in many communities within this group of children taking on the responsibilities for care.

Nalini Malik, one of a growing number of young Asian carers, told us about her experiences as a carer in 2015 looking after her father:

'I have to help my father to the bathroom and it is difficult because he is a tall gentleman and it is killing me to have to help him get up from the bed or get up from the floor, and his condition has become ever worse. He had renal failure and he has to go for renal dialysis and basically, he is very ill, and he relies on me for everything. I have to help him to have a shower or have a bath, and sometimes he's incontinent.'

The establishment of co-terminus local and health authorities, which resulted from the restructuring of local authorities from 32 to eight, brought many benefits to local planning and in particular opened up new opportunities for carers' organisations to become properly recognised partners, and many have become central to the effective functioning of the new community planning partnerships. The new 'challenge and support' performance management regime for social work departments (with its hit squads and directives to poorly performing statutory commissioners to develop a greater mixed economy of care) has created opportunities for the larger carer organisations who have developed service delivery (e.g. domiciliary care) units alongside their campaigning, information, advice and guidance work.

Planned, preventative support is now a more common feature than in the past and many carers cite the increased involvement of carers' organisations as a key contributory factor. The twenty-first century review of social work took longer than most expected to have an impact, but in fact carers' organisations were some of the first to track changes in perceptions that a greater clarity of roles and responsibilities was leading to better outcomes for carers, and that there was an emerging greater professional respect for a new breed of 'expert' carers. Similarly, the application of remote caring technology and monitoring and 'telecare' is starting to have an impact, especially in rural areas, where special funds have led to the development of communication networks to allow 'remote' carers to stay in touch with carer organisations and service providers alike.

In a repeat of a survey carried out in 2005, 72% of carers felt positive about the future. However, for carers at the heavy end, the intensity of the caring experience has increased and the health and social dis-benefits have become worse for all groups except young carers, where there has been good progress. Based on excellent research, a national young carers strategy and framework was developed in 2007, and many local authorities have chosen to target their Community Bond allocation at addressing the needs of young carers and improving their educational attainment. However, the number of young carers from BME groups has continued to rise with the overall increase in BME groups as a percentage of the population, prompting some BME leaders to claim that minority communities remain outside the community planning partnership processes, which are dominated by Eurocentric models of care, and that majority groups are 'simply spending the money on themselves'.

The benefits of significant growth in BME immigration has mostly been seen in the number of BME workers entering the health and social care workforce, filling long-term vacancies at all levels and professions. However, child poverty is more common among these new Scots, adding to an already persistent children-in-need problem. This is only partially mitigated against by the expanded range of a multi-lingual workforce that is able to address the specific cultural needs of people and families with support needs.

Attempts by government to set targets for the greater use of a mixed economy of care (following a review of commissioning and contracting which showed wide variations and poor practice amongst many authorities) was met with wide-scale resistance from community leaders, particularly in rural areas, citing outcomes from south of the border as a result of similar reforms. Nevertheless some 'modernising' authorities have developed more robust arrangements that have led to a number of larger care providers establishing offices in Scotland in anticipation of further reform.

The views of carer groups about the effects of policy and public service reform on caring communities are highly polarised. Those who have more positive experiences of caring point out that there are now better public services in place to support their needs. The improved funding for social care and health have benefited many carers, particularly those from more deprived backgrounds. Those who have more critical views, however, believe that the current system does not offer enough tailored support and choice within a system which is still very centralised and driven by government departments. The local authority and the NHS, still the main providers of services for carers, are often criticised by this group for failing to give sufficient attention to the individual needs of carers, and for being dominated by 'provider' interests. The 'choices' which are enabled by the system still occur after a comprehensive assessment of need which many carers describe as 'over-professionalised', and where only those vociferous and insistent enough can force full provision of their needs.

In addition, carers from more prosperous communities believe their needs are ignored in favour of those living in deprived areas. Maggie Dixon, a representative from a caring organisation in a prosperous suburb of Edinburgh recently criticised the local authority for its 'obsession with the worst off.'

Health

The health of the Scottish population has improved steadily over recent years, with improving survival rates, reduced mortality for major diseases, including cancer, strokes and coronary heart disease, and steadily increasing life-expectancy. This has been attributed to the increase in NHS capacity, the investment in innovative new services and health technologies, reduced long waits for treatment, but also general growing prosperity.

There has been a reduction in health inequalities, but this has been offset to some degree by predominance of unhealthy lifestyles. Scotland is still seen by many as the binge drinking capital of Europe, and a haven for unhealthy eating and for high levels of smoking. While there has been an increase in life expectancy, many of those living longer do not lead active lives, and are afflicted by chronic illnesses. In addition, there has been an increase in some mental health problems, including depression, schizophrenia and eating disorders.

Society and lifestyles

The gap between the wealthy and the less prosperous has narrowed over the last 10 years. While the income of the top 20% in Scotland has grown, the income of the lowest 20% has increased more markedly, owing largely to an increasingly redistributive taxation system. In spite of this, many areas of Scotland are still classified as deprived, with high levels of unemployment and crime, poor quality housing, and lower standards of health prevailing in many areas. There has, however, been a range of improvements in many of the poorest areas and a reduction in the absolute numbers of people living in poverty. The worst affected areas of Scotland continue to be the former industrial areas, but after increased investment from Government, including the setting up of business promotion zones,

living conditions and the quality of life has improved, although long-term unemployment is still a problem.

There is some evidence to suggest that the focus on cohesive communities and the duty of people to participate actively in society is changing values and behaviours. Recent polling research has identified a strong upward trend in the number of people claiming both to 'trust their neighbours' and 'feel part of the community'. Participation in recent local elections has hit a 10-year high and more people than 10 years ago take part in volunteering, but this is declining. Owing to the government's massive extension of affordable house building and subsidised mortgages, there has been a 20% rise in house ownership over the last 10 years.

However, the past decade has seen a continuation of some worrying trends. The breakdown of the traditional model of the family has continued, with more people living on their own, rising divorce rates and an increase in the number of single mothers. Racial tension has increased as the immigrant population has grown, and the pattern of attacks and clashes between ethnic groups in Scotland's cities is worrying. The numbers of people reporting that they mistrust 'other ethnic groups' has risen in the past few years, a trend that the government is keen to reverse.

Annex: Scenario Trends

The following graphs are outputs from the economic modelling strand of the Care 21 Future of Unpaid Care research project. An economic modelling tool has been developed by OPM and Experian Business Strategies for the purposes of predicting the likely demand for unpaid care in Scotland over the next decade. The model is based upon core data from the Scottish Household Survey, and has been developed with scenario planning in mind such that assumptions about key variables thought to impact upon unpaid care (age, household tenure/ deprivation, co-habitation, dependents), can be changed.

Figure 1: Population

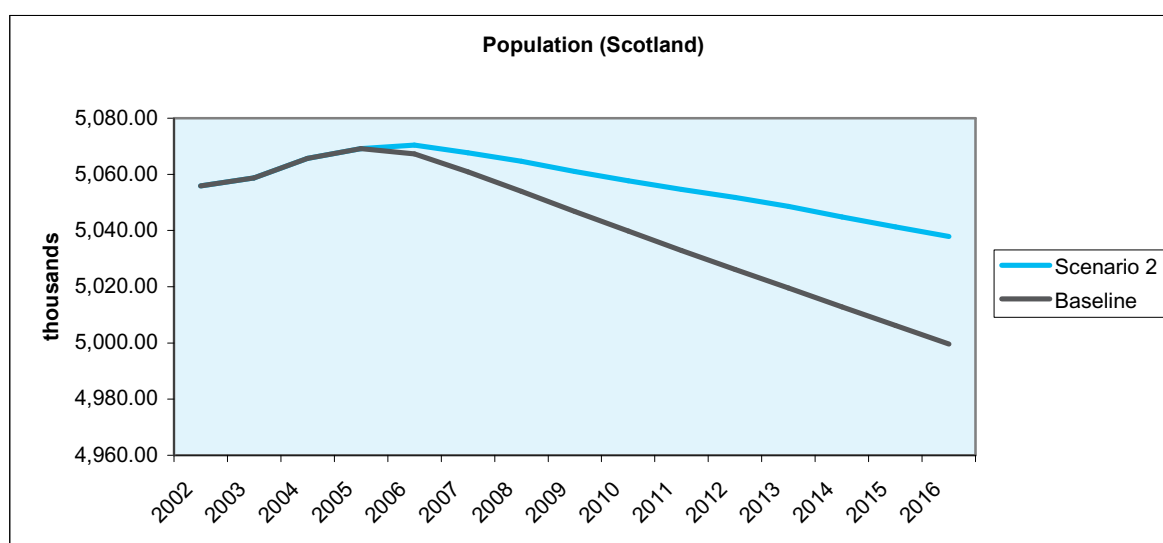


Figure 2: Change in population by age band

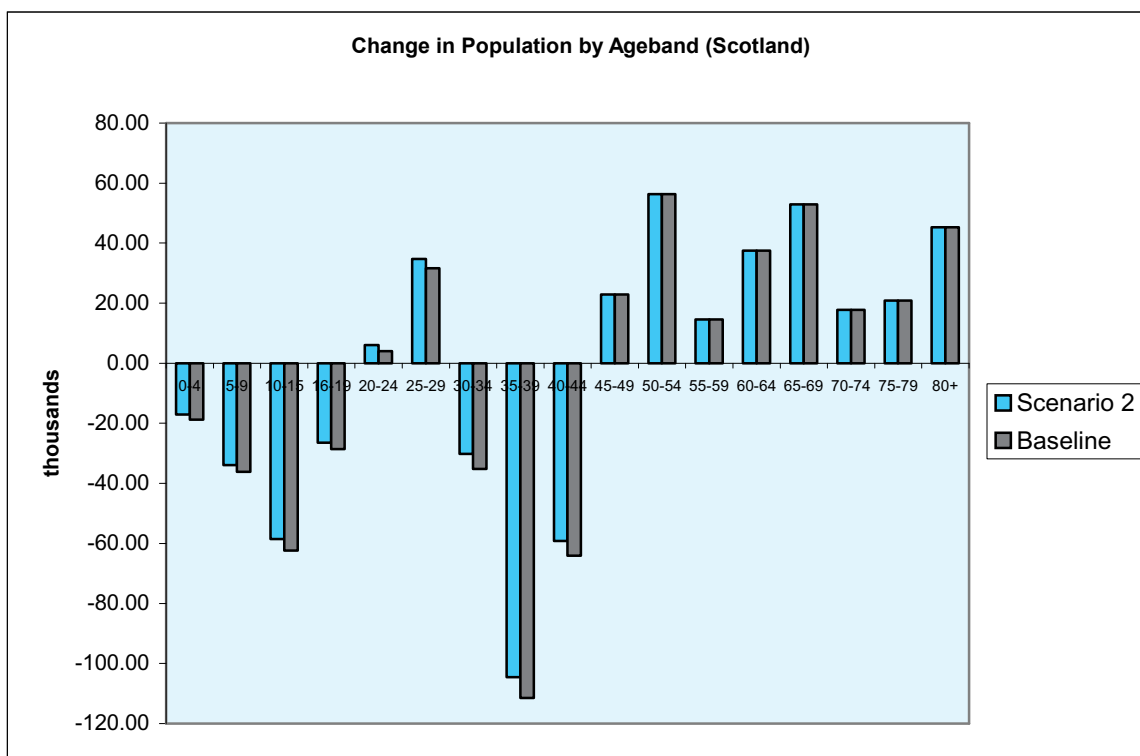


Figure 3: Unpaid care

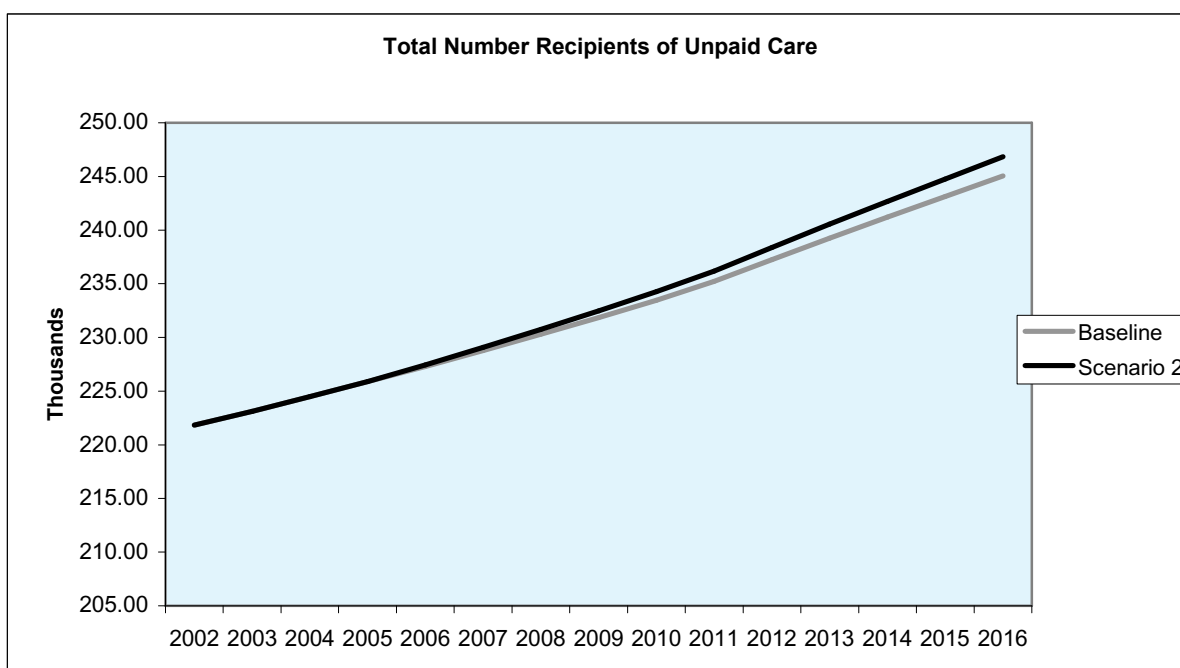


Figure 4: Tenants

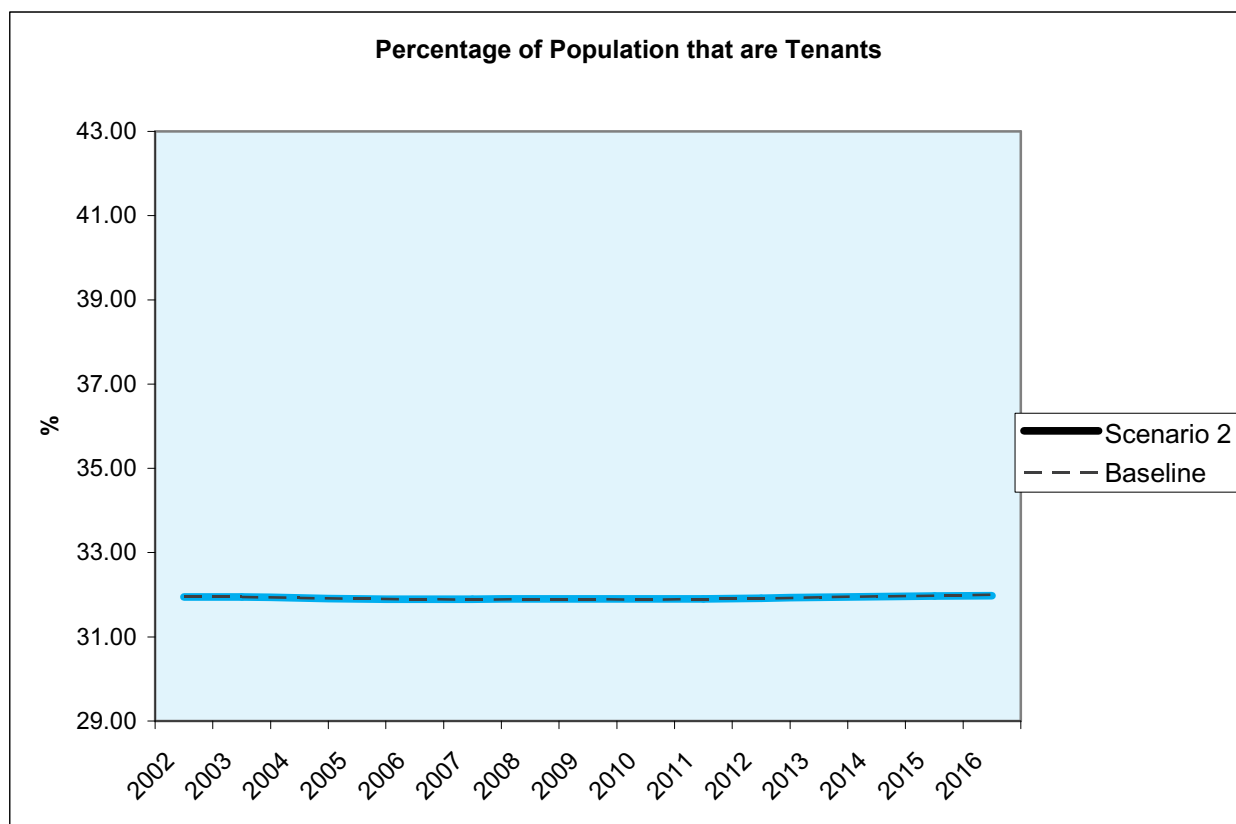


Figure 5: Co-habiting elderly

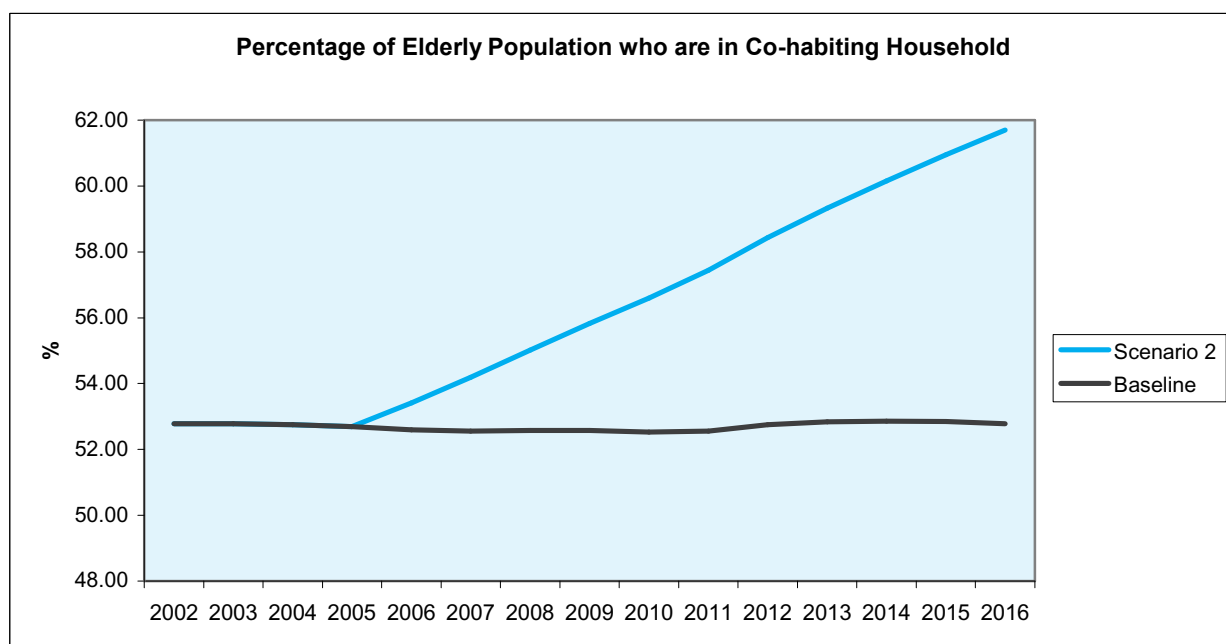
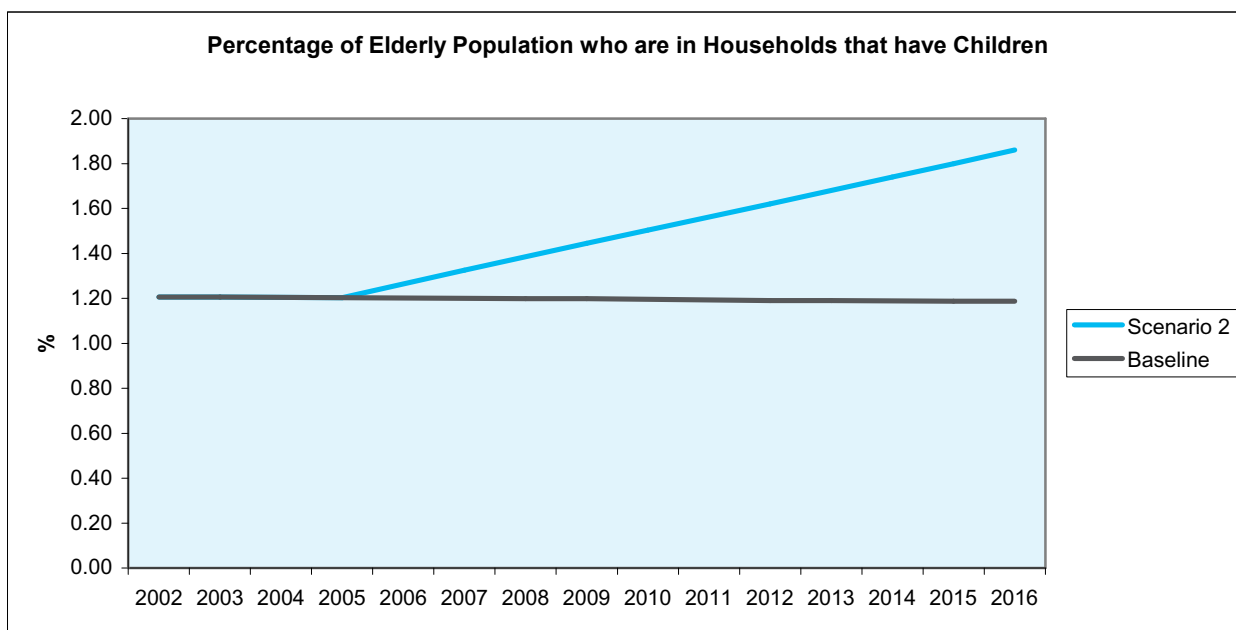


Figure 6: Elderly in households with children



Scenario 3. Choice and division

Introduction

In 2015 the Scottish Parliament is led by a Labour/Liberal Democrat coalition, with the support of three right leaning independents. Calling itself a 'modernising' government, the administration is strongly focused on delivering what it calls 'pragmatic solutions for a modern Scotland.' The past decade has seen Scotland become one of the major success stories of Europe. Scotland now has a reputation for having a highly flexible and knowledge driven economy, backed by high levels of spending on public services. GDP growth has been at a steady average of around 2% over the last 10 years, although this has dipped slightly in the last two years. In a bid to reduce its high levels of government borrowing – fuelled by the high levels of public investment which have now taken public spending in the UK above the European average – the government has had to reign in investment dramatically, decreasing spending as a share of GDP for the first time in over a decade.

GDP growth has been high and the ability of Scotland to attract both UK and multinational firms has placed Scotland in the top five EU countries for inward investment. Financial service companies, major multinational companies – including a new wave of successful Chinese, Indian and Brazilian companies seeking a European base, and smaller but growing knowledge and technological companies from around the world – have all flocked to Scotland. Whilst much of this investment has focused on the Edinburgh region, the rest of Scotland has also grown and benefited greatly.

Scotland's sustained investment in education and skills over the last decade, with Scotland seeing much higher levels of upward mobility of people from disadvantaged backgrounds moving into further and higher education than England, has meant it has one of the highest skilled workforces in Europe. In the past year two major bio-medical technology developers have established operations in Scotland and a major Chinese car manufacturer has announced plans to establish its European development operations in Glasgow. Average income in Scotland is rising and overall levels of poverty levels have decreased, although poverty is still prevalent in many areas of Scotland.

Scotland's economic growth has not come without its costs. It is now regarded as one of the hardest working countries in Europe – with employers working long hours and taking fewer holidays. With the decline in the power of the EU, pegged back with the collapse of the single European currency in 2008, employers pay scant regard to European employment directives, and few cases are challenged. The failure of the Westminster government in 2009 to oblige people to save more and enter private pensions schemes has meant that Scotland is also a low saving country. This year, the UK has become the first country in Europe to extend retirement age to 70, although in many parts of Scotland people were already choosing to work until at least this age.

For the last five years, Scotland has seen its population start to grow, reversing a downward trend which started in the 1970s. Although the population is still ageing – with more people living to over 65 than ever before – there has been a steady influx of immigrants over the last eight years. Along with slightly increasing birth rates, the steady arrivals of new, younger immigrants has meant that Scotland's population is growing and, in a reversal of recent trends, there has been a faster growth of under 45s than over 65s. With some aplomb, demographers and the ministers behind the 'Live in Scotland' initiatives to attract immigrants, now claim that 'Scotland's demographic time-bomb has been diffused.'

The working environment in Scotland is also changing. More people are now working at home, part time and changing careers several times during their working lives. While on the one hand this has given workers greater control over how and where they work, it also increases the sense of isolation and insecurity amongst many employees. Experts believe work-related stress is reaching epidemic levels in Scotland and long-term work related ill health is very common.

Scotland has become one of the most popular destinations for immigrants from outside the EU. East European immigration has finally replaced Commonwealth immigration, with large numbers of East European workers coming to Scotland and finding mostly low paid work but also helping to alleviate recruitment and retention problems in key sectors such as health and social care. The rapid

increase in the ethnic minority population has brought huge benefits and helped Scotland to fuel its economy. However, it has also brought with it an increase in racial tension and, as these communities thrive and spread out of the traditional urban centres of Edinburgh and Glasgow, an increasing resistance amongst some sections of society to immigration. The recent terrorist attack in Edinburgh has increased the feeling of mutual distrust amongst communities. So far this has been fairly low level and isolated amongst a few groups, but the Scottish administration has expressed concern over the issue.

Public services

Helped by rising prosperity, and its ability to point to demonstrable improvements in key public services, the Scottish administration – supported by the Labour Government in England – has continued to pursue a radical course of public service reform. The programme of reform is underpinned by two central themes: ‘promoting user choice’ and ‘building community resilience’.

Building on the tentative steps taken by the previous administration to expand service user choice into a range of service delivery areas, the current regime has continued to expand the service user choice agenda. Aware early on that their agenda could not be delivered through state funded monopolies, the Government has sought to greatly diversify the range of organisations providing key public services, opening the door for more private and voluntary sector organisations to acquire a role in public service provision. In order to give patients greater choice, patients are now able to choose a provider of their treatment from local menus of accredited providers. To promote greater localised and professional control over the choice agenda, the lion’s share of NHS primary care budgets are devolved directly to GP practices that purchase services on behalf of patients. In relation to many social care services – such as day care, respite, and home care services – more money is now given directly to service users who can use their ‘care vouchers’ to purchase services from a range of locally accredited providers, many of whom are in the voluntary and private sectors.

The second theme underpinning reform, building greater community resilience, is focused on empowering communities to take a greater role in improving local services and enhancing the quality of life. According to First Minister Leslie McDonald, the initiative is about ‘giving local people the resources to help themselves’. The new policy is underpinned by several structural and financial changes. While local authorities are still seen as the predominant source of democratic community leadership, new neighbourhood forums have been established to direct and determine changes to local services, including social care, environmental services, housing and schools. The new forums, while ultimately accountable to the local authority – although the representatives who sit on these are elected through a bi-annual e-vote – have the power to develop local plans, set targets and distribute funds. In order that the forums promote greater choice, they are allowed to purchase services for local people from a range of providers, including the private and voluntary sectors.

The biggest beneficiary of the above policy changes has been the voluntary sector, growing in size, professionalism and capability. There are now a number of ‘super’ voluntary organisations which run a range of health and social care facilities and services in local areas, competing against private and NHS providers to be the top choice for local people. Care Select, a new super carers’ organisation, now delivers carers services across most local authorities in Scotland, including social care support, respite, health visiting and adaptations.

Supported actively through a number of government policies, the role of volunteers in supporting local communities and providing public services has seen a steady growth in the last 10 years. The rise is partly due to the decision by the Inland Revenue to provide tax reductions to employers who entered volunteering schemes, producing a whole new army of volunteers, but it is also due to the growing popularity of volunteering in general. This does not mean there has been universal rejoicing at the new commitment shown by people to help others. *Volunteering Today*, a recently launched magazine devoted to volunteering issues, called the upsurge in volunteering ‘a middle class phenomenon’ sparked by socially responsible businesses trying to do the right thing. While the article goes on to say that all volunteering is good, it criticises most new volunteers for failing to help deprived communities and ‘sticking to their own.’

The changes to public services driven by the government have both their advocates and critics. The advocates of change believe that the public services are now working harder to meet the needs of local people, bringing in, where necessary, the expertise and additional resources of the private and voluntary sectors to boost choice and raise capacity. The critics, while encouraged by the growth of a stronger voluntary sector, argue that choices are only being made available to the better off and better educated at the expense of citizens in more deprived areas. One prominent left wing critic commented last week: 'For most people, a good quality local school or hospital is what people want – not a labyrinth of different choices. You need a degree in choice just to understand what to choose.' The Neighbourhood Forums, by taking powers away from local authorities and central government, are less accountable for the decisions they take. In addition, with less central control and direction, it is argued, huge gaps are opening up between higher and lower performing organisations.

Health and social care

Increased prosperity is a strong determinant of improved health, so it is unsurprising that Scotland in 2015 is a healthier nation. As a result of sustained investment in the NHS, the number of people dying from the three main killers in Scotland, strokes, cancer and heart disease, has declined steadily over the last 10 years. The investment in new medical technology and drugs has enabled the NHS to help more patients treat and manage chronic illnesses like cancers and multiple sclerosis, heart disease, and arthritis – prolonging people's lives. Life expectancy for both men and women has increased as a result.

Although people are living longer, it is not necessarily the case that the quality of life of older people is improving. For older people with high levels of savings, who have lived more healthy lives and are relatively prosperous, the later years of their lives can promise a high standard of living. More older people in Scotland are now engaged in healthier lifestyles, working later into their lives, and taking part in volunteering and charity work.

For those older people who do not have savings, live in relative poverty and who have not lived healthy lives, old age can be very challenging. With less support available through state provision – and fewer residential care home places than ever – life for this group can often be a struggle – with many living with the pain and difficulty of complex care needs, a lack of income, and low level of state support. In a growing number of cases, this group is almost entirely reliant on the help of friends, family and local charities. While life expectancy may have increased for this group, the quality of life has declined.

Carers

For the last 10 years, Scotland has seen a steady number of people who have unpaid caring responsibilities. The speed of the growth, even with the changing demographic picture in Scotland which has seen the population of older people steadily increase, has surprised even the experts on caring in Scotland.

There has been a growth in the numbers of carers across all age groups and social classes. However, the growth has been most marked amongst two groups, lower income and socially deprived groups, and worryingly, amongst younger people of all social backgrounds.

There are two main reasons for the growth in the number of socially deprived carers. The first has been the steady decline in the level of support and provision provided by local public services for both those who need care and those who provide care. Although vigorously denied by the Government, the recent reduction in public spending, and the shifting of resources to support choice in relation to acute care, has led to a reduction in many carers' services, such as day care, respite and home visits. The second reason is that, within more deprived family circles, there is a growing number of older, and younger, people who have complex care needs, such as heart conditions, arthritis, and severe mobility problems. While the NHS and local authorities have sought to increase some services to those with these care needs, the increases have not kept up with the growing numbers needing care.

The growth of younger carers has presented a major challenge to the Government. Although still much lower in number than older carers, younger carers (under 25s) are growing steadily in numbers. The reasons for this are complex; however, most commentators put the growth down to the increasing numbers of people who have to care for older relatives and friends. This is due to a continuing growth in the number of older people while the number of younger people is declining. It may also relate to the growing number of younger black and minority ethnic people who care for relatives.

More worryingly for champions of social equality, there has been very much slower growth in the numbers of carers among more affluent social groups, suggesting that people in these groups have been able to purchase better care for friends and relatives from the private and voluntary sector, or that those in their social and family circles require less care than others.

Marie Carmichael, a carer of a husband with cancer, is just one of Scotland's growing number of low income working carers. She told us:

'I work as a secretary and then I go home and I'm caring. You know, generally just washing. Sometimes he'll think to put it in, sometimes he won't, its just general household things really. He gets his own breakfast, he is still able to do all that, and he still goes off to ballroom dancing once a week and he goes to a psychologist. So, he's still active, but he's getting very forgetful. It's possibly his age, possibly his medication and although they say he'll die of old age before the cancer, because its prostate cancer, I have still noticed a big difference in him in the last two years.'

A Chinese mother of two, who cares for a son with cerebral palsy – one of a growing number of BME carers – told us about the frustration she has with local service provision.

'Services are there but they are not culturally sensitive. Who don't know how to cook Chinese, who don't know how to communicate with Chinese people ... Another service we use is the respite service so once every five weeks he might have a week or weekend stay in a respite centre that gives my husband and myself and my little boy some sort of respite too, so that we can forget about the caring role. But my main point is, though services are out there, if you do not know the language, you know nothing about it.'

In 2015 there is now far greater recognition that unpaid carers represent the largest care force in the UK. Carers and their representative bodies in most localities are far more integrated in the planning and delivery of care services generally. Statutory carers' assessments are a regular feature, and are augmented by a type of self-assessment which has increasingly become a feature of social care since the implementation of the Health and Social care White Paper in 2007, which gave considerable emphasis to the concepts of co-production, personalisation and choice. This has not necessarily translated into an entitlement for services, as the framework of entitlement and eligibility that the government has developed has become ever more complex, meaning that only those who are able to navigate the complexities of the system, or those who clearly fall below any means testing, gain access to the full range of services.

Carers' health has become a core public health issue, and a number of successful schemes have been developed with Scotland's larger employers' occupational health units to fund jointly counselling for carers who balance part-time work with caring responsibilities. An overhaul of the benefits system has created greater flexibility between working and caring and this has contributed to a rise in caring becoming a realistic and positive life choice for many. 'Expert' carers are a feature of many local systems, and many carers supplement their income delivering modules on issues relating to unpaid care as part of professional training schemes. Similarly, the application of remote caring technology and monitoring and 'telecare' is starting to have an effect, especially in rural areas, where special funds have led to the development of communication networks to allow 'remote' carers to stay in touch with carer organisations and service providers alike.

A review of commissioning and contracting in social care exposed wide variations in approaches to market management and the development of the mixed economy in social care. The Government

balked at prescribing the way forward, so only a small number of 'modernising' authorities have pursued this area of reform. One area, respite care, has proven resistant to several attempts at reform and expansion. In a recent survey, carers report a chronic shortage of suitable, timely, local and appropriate respite care, and this is particularly so for carers in rural areas and for BME groups. The recent restructuring of local government, and consequent reduction of 32 authorities to eight, has allowed greater economies of scale, shared risk arrangements for new capital projects and greater purchasing power vis-à-vis the private sector, which has been exploiting under supply for some years. But some of the gains here have been offset by the proliferation of area-based initiatives, partnerships and zones for targeted provision with mixed geographical boundaries.

One of the more significant gains has been the effect of 'whole systems' working arising from compulsory multi-agency carers' strategies, which have energised traditional non-care services such as leisure, transport and environment services to consider the impact on the quality of life for carers. In most cases, these approaches are a bi-product of quality-of-life strategies for older people, and have yet to translate the benefits to positive outcomes for other age cohorts.

Society and lifestyles

In 2015 Scotland is a country of great contrasts. While the gap between the most and least well-off has reduced slightly over the last ten years, there are still huge levels of inequality. The contrast between those in the top strata of society, and those in the lowest, could not be greater. For example, there are parts of Edinburgh where average incomes are now in the region of £100,000 per annum, where household ownership is at 90% and where most children attend private school; while in parts of Glasgow incomes can be as low as £13,000 a year in some households, large parts of the housing stock are unfit for human habitation and crime is rife while schools are failing.

Although poverty has fallen overall, there are still pockets of severe deprivation where poverty, crime, low quality housing, and low educational achievement are concentrated. In these communities, older people can be some of the most deprived people, cut off from family networks, good public services, and sufficient levels of income.

Scotland's values, behaviours and cultures are changing fast. The number of people living on their own is on the increase, while rates of marriage have remained static for a number of years at a record low. In terms of people's views of others and the communities they live in, there is a marked growth in 'individualism' and a declining support for 'society and community'. More people when surveyed now believe that 'there is no such thing as society'. Although support for close friends and family remains strong, fewer people take part in social and community activities, such as the Scouts, Social clubs, charity events, local festivals and sporting events.

Attendance at church, apart from in the black and minority ethnic communities where it is increasing, is declining fast and the number of people identifying with a major political party has declined, although environmental and single issue politics seems to be on the increase. For example, more people texted and emailed in support of the 'Vancouver 2010 declaration to end poverty in Africa' than voted in the last Scottish Parliament elections.

Persistent child poverty threatens to undermine the positive gains made to reduce the number of young carers overall, as family break-ups, poor work-life balance and poor parenting skills create an invisible cohort of young carers, particularly among newer immigrants insufficiently 'plugged into' the system.

Critics of the modern Scotland continue to report a decline in social values and behaviour. Antisocial behaviour – increasingly stamped on through punitive measures such as 'family fines' that penalise the whole family for the crimes of individual family members – is on the increase, while many people point to there being a breakdown in 'mutual respect'.

Annex: Scenario trends

The following graphs are outputs from the economic modelling strand of the Care 21 Future of Unpaid Care research project. An economic modelling tool has been developed by OPM and

Experian Business Strategies for the purposes of predicting the likely demand for unpaid care in Scotland over the next decade. The model is based upon core data from the Scottish Household Survey, and has been developed with scenario planning in mind such that assumptions about key variables thought to impact upon unpaid care (age, household tenure/deprivation, co-habitation, dependents), can be changed.

Figure 1: Population

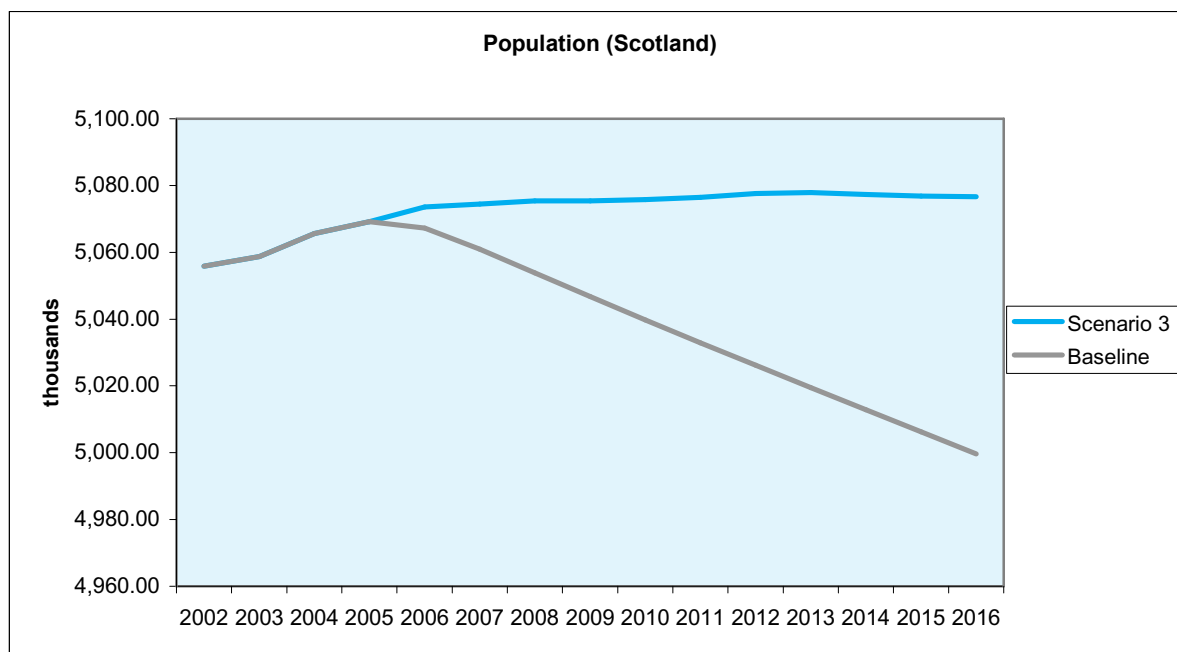


Figure 2: Change in population by age band

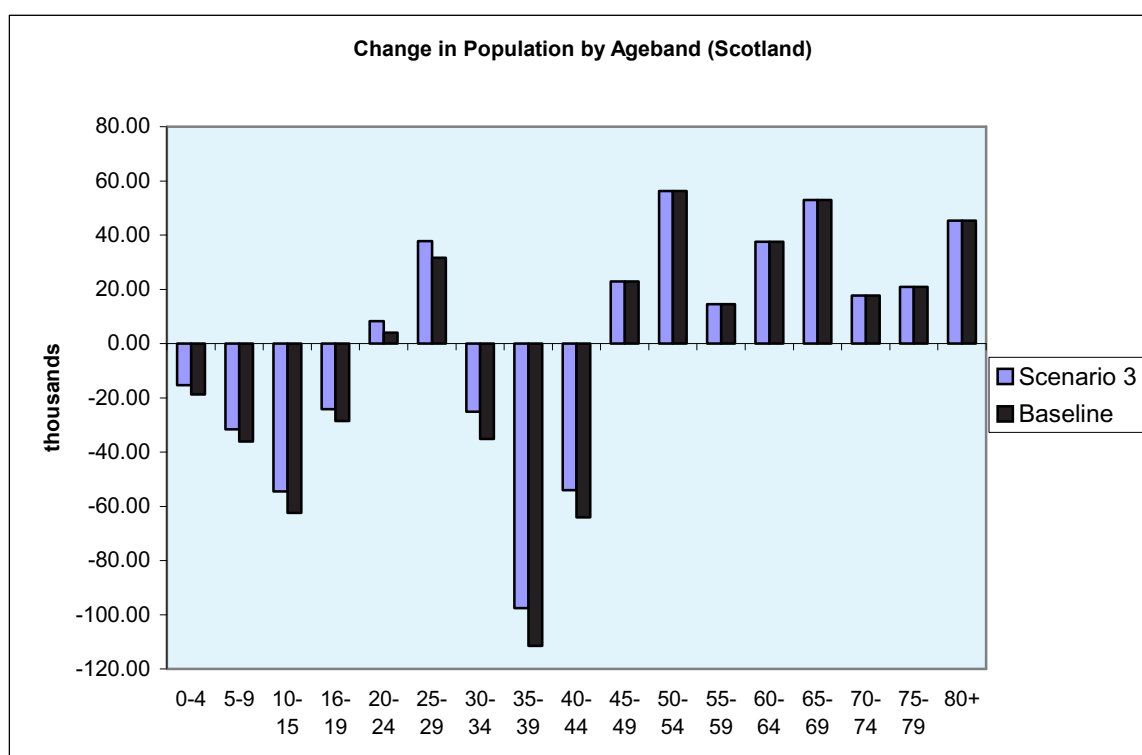


Figure 3: Unpaid care

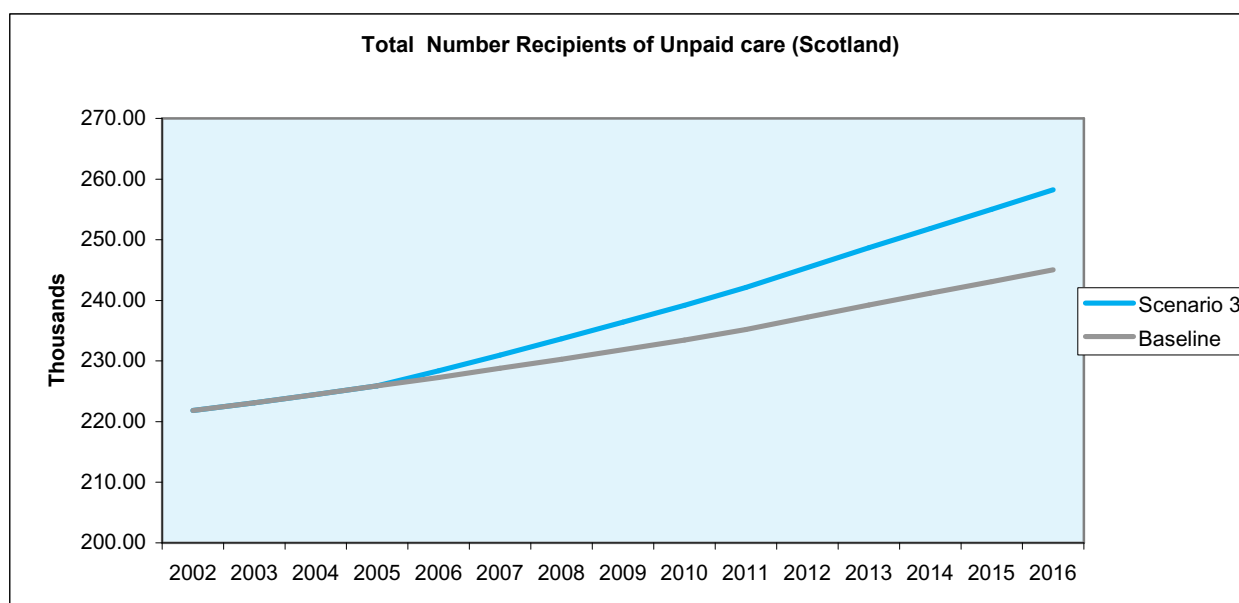


Figure 4: Tenants

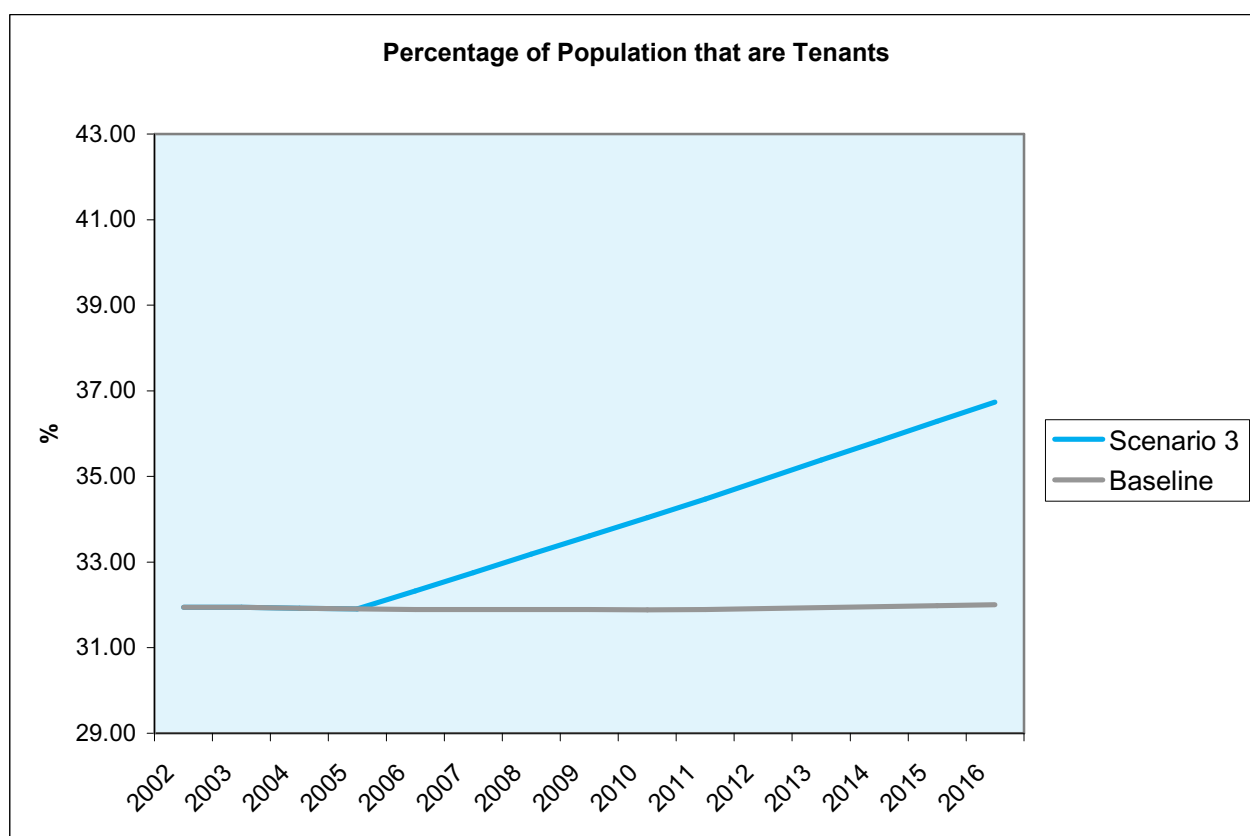


Figure 5: Co-habiting elderly

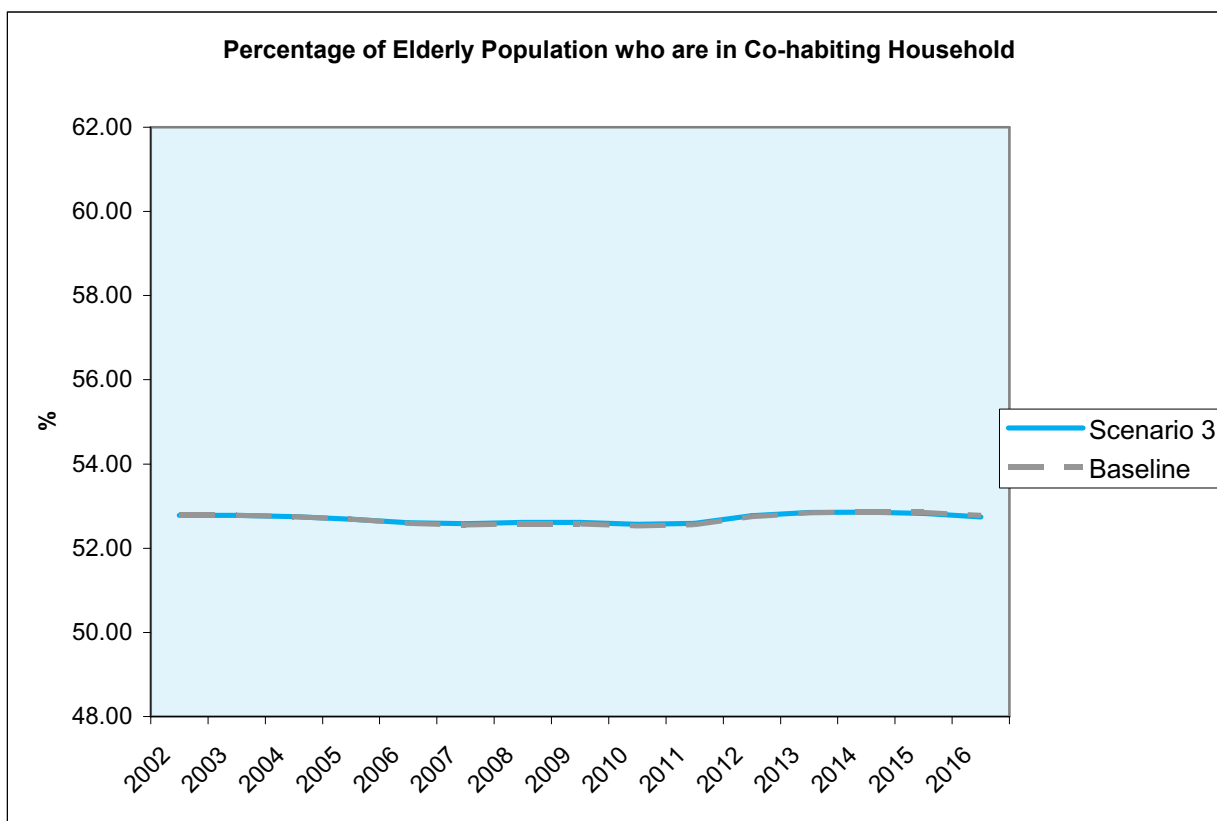
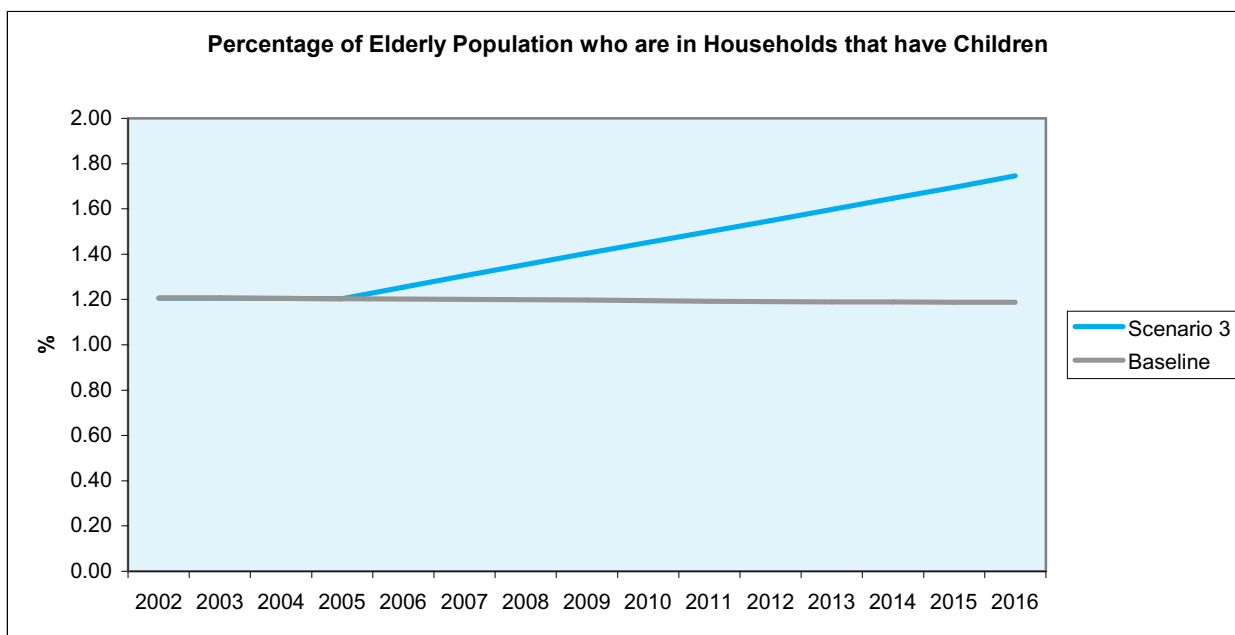


Figure 6: Elderly in households with children



Annex C1: Note on 'Delphi' methodology

The research methodology on which the two scenarios are based was developed in precise stages. It draws on the experience we have gained from doing similar studies over the years. We began by establishing a panel of experienced individuals, chosen for their broad understanding of the complexities and dynamics of Scotland's public service provision. This panel was made up of over 1000 people working across the public services – including representatives from central and local government, health, education and the police – as well as from representatives of the voluntary and private sectors.

Stage one: Establishing the panel

OPM approached approximately 450 senior individuals from a wide range of organisations all over Scotland. We explained the objectives of the survey as well as the proposed process: a modified Delphi survey combined with a 'cluster analysis' technique. The nominations were later added to by combining Care 21 nominations and a number of mailing lists. A 'panel' of over 1700 people was subsequently established.

Stage two: First-round questionnaire

At the beginning of December 2004, a first round questionnaire was sent to the panel members. They were asked to predict three to five external changes which they believed would have a significant impact on unpaid care over the next decade. We asked them to be as detailed as possible in their responses, particularly on the direction, level and impact of the changes. The questionnaire can be found in annex C2. Approximately 380 people responded to this first-round questionnaire.

Together, they gave us over 2000 individual predictions. These open-ended responses, or 'change statements', were the only source used to construct the second-round questionnaire. They were also used to provide specific detail in the three scenarios.

Stage three: Second-round questionnaire

The second-round questionnaire was sent to the panel in March 2005. This questionnaire aimed to measure similarities and differences in the panel member's opinions and to provide us with more information for the scenarios. Specific questions covered changes that might possibly occur in public services and the general environment over the next 10 years. Using a scale from one to five, the panel members were asked to indicate what they believed the likelihood was of each change occurring by the year 2014. The questionnaire can be found in Annex C3. The response rate to the round-two questionnaire was 22 % per cent, typically high for a survey of this nature. The responses were analysed using a statistical cluster analysis technique with the statistical IT tool, SPSS. This technique measured the similarities and differences in the responses and grouped the respondents according to their propensity to agree. The analysis identified three relatively evenly spread clusters of predictions amongst the panel. These are referred to as clusters one, two and three. We did not tell panel members which cluster they belonged to.

Stage four: Constructing the scenarios

The responses from the second-round questionnaire were used separately to construct the scenarios. In each case, the change statements derived from the questions were collated into several categories:

- Political overview

- Economy and workforce
- Public sector
- Health and social care
- Carers
- Society and lifestyles

We used the crude results from the questionnaire to develop a profile of each predicted future and then used these profiles to write up the narrative accounts. The point of these narratives was to make each scenario more impressionistic than the crude survey would have read and so, to help the scenarios 'come alive', we asked Care 21 representatives to comment on them.

Finally, we named the scenarios: 'Prosperity for some', 'Inflexible cohesion' and 'Choice and division'.

Annex C2: Delphi – round-one questionnaire

Several external factors will have a significant impact on unpaid care in Scotland in the future: demographics, the economy, government policy, technological developments, environmental issues and social attitudes. Please **predict three to five specific changes** related to any of the factors above, which you think will affect the shape and nature of unpaid care over the **next ten years**.

We need you to be very specific in the nature of your response: for example, 'changes in the funding structures' will not help us. Your prediction about the **nature, direction, scale or implication** of the changes will. For example, predictions could include statements of the following nature:

- *'The rising number of older people in Scotland is likely to lead to an increase in the demand for unpaid (as well as formal / statutory) care in the future.'* or
- *'An increase in paid employment may lead to fewer people with availability to provide unpaid care.'* or
- *'Carers strategies are likely to lead to lots of unmet need being uncovered.'* or
- *'Employers will start to realise the business benefits of supporting carers in the workplace, and this will make it easier to care.'* or
- *'Most schools are unlikely to have the resources to work with partners to focus on reducing the caring responsibilities of school age young persons, so the number of young carers will probably be about the same.'*

Q1: Please predict 3-4 changes that are likely to affect the demand of unpaid care over the next ten years

1.	
2.	
3.	
4.	

Q2: Please predict 3-5 changes that are likely to affect the provision of unpaid care over the next ten years

1.	
2.	
3.	
4.	

Thank you very much for your time. Please return to OPM as soon as possible and no later than Monday 6 December to OPM (Office for Public Management), 252b Grays Inn Road, London, WC1X 8XG.

Annex C3: Delphi – round-two questionnaire

In this questionnaire you will find a set of statements relating to factors that are likely to affect unpaid carers in Scotland in 2015. The statements are not ordered by priority or importance.

In section A, we ask you to record your predictions about the direction of change; in section B, we ask you to consider how likely it is that certain changes will occur by 2015; and in section C we ask you to choose between pairs of statements about factors that might affect unpaid care in 2015.

We will treat your responses confidentially, and responses will be destroyed on completion of the data gathering exercise. Please complete and return the questionnaire in the pre-paid envelope **no later than 8 April 2005**.

Thank you very much for your time.

Section A

Please record your predictions about the each of the following issues.

Please avoid middle scores if you can.

Question: By the year 2015, how much change do you think there will be to each of the following? (please tick the appropriate box for each question)

Issue	There will be a major decline/decrease	There will be a slight decline/decrease	There will be no change	There will be a slight increase/improvement	There will be a major increase/improvement
A1 The level of demand for unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A2 The number of people providing unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A3 The tax-generated income made available for health and social care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A4 Involvement of voluntary sector agencies and community groups in supporting unpaid carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A5 Public acknowledgement of issues facing unpaid carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A6 The Scottish Executive's understanding of, and emphasis on, issues facing unpaid carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The future of unpaid care in Scotland

Issue		There will be a major decline/decrease	There will be a slight decline/decrease	There will be no change	There will be a slight increase/improvement	There will be a major increase/improvement
A7	The Scottish economy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A8	The number of people in society feeling socially excluded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A9	Social acceptance of cultural and racial diversity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A10	The gap between rich and poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A11	Birth rates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A12	The general physical health of the population	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A13	Levels of personal savings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A14	The number of people in paid employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A15	Flexible working arrangements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A16	The number of single-person households	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A17	Life expectancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A18	Divorce rates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A19	Levels of obesity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A20	Government investment in public transport	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A21	The number of people feeling isolated in society	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A22	People's disposable income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Issue		There will be a major decline/decrease	There will be a slight decline/decrease	There will be no change	There will be a slight increase/improvement	There will be a major increase/improvement
A23	The number of active elderly people (over 65)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A24	The level of affordable housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A25	Westminster's understanding of, and emphasis on, issues facing unpaid carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section B

Please record how likely you think it is that the following changes will occur by the year 2015.
Please avoid middle scores if you can.

Question: How likely do you think it is that each of the following changes will occur by the year 2015? (please tick the appropriate box for each question)

	Impossible	Very unlikely	Uncertain	Very likely	Virtually certain
B1 Unpaid carers will increasingly be able to articulate their needs, thus placing greater demands on statutory bodies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B2 Carers will be given a more active role in assessing the needs of the person cared for	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B3 Individual care plans will be used less	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B4 People in need of care will be more reluctant to ask for unpaid support, not wanting to appear to be a 'burden'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B5 It will be increasingly difficult to recruit qualified staff to the care profession	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B6 The scope of the definition 'disability' will widen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B7 The use of respite care will increase	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B8 Legal requirements for unpaid carers will become stricter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B9 Legal requirements for paid carers will become stricter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B10 There will be fewer young carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Impossible	Very unlikely	Uncertain	Very likely	Virtually certain
B11 There will be an increase in the number of people with complex health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B12 Employers will increasingly adopt carer-friendly policies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B13 There will be fewer, but larger, hospitals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B14 Voluntary agencies and statutory service providers will increasingly work together to deliver care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B15 Voluntary agencies and statutory service providers will increasingly work together to support and work with those providing unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B16 People will feel less responsible for the health and well-being of their relatives and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B17 Carers will be given more say in determining how the needs of the cared for are met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B18 There will be an increase in the proportion of men providing unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B19 Far more training will be offered to support unpaid carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B20 The public will increasingly accept the need to ration health and social care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B21 There will be more people providing lower levels of unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The future of unpaid care in Scotland

	Impossible	Very unlikely	Uncertain	Very likely	Virtually certain
B22 There will be fewer people providing higher levels of unpaid care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B23 The public will increasingly accept the need to care for their relatives and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B24 A higher percentage of people in need of care will live with support in the community rather than in institutions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B25 Advanced stages of chronic diseases such as cancer will be managed in the community more often	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B26 Paid care will be rationed more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B27 Higher survival rates of premature babies will lead to more children requiring parental support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B28 People will increasingly live longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B29 Euthanasia will be legalised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B30 People will retire from work later	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B31 People will lead healthier lifestyles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B32 Tobacco smoking in Scotland will be banned	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B33 Pensioners will have a lower disposable incomes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B34 Average working hours will reduce	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Impossible	Very unlikely	Uncertain	Very likely	Virtually certain
B35 Unpaid carers will increasingly require specialist knowledge about people's complex and multiple needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B36 People will increasingly become self-centred	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B37 Emphasis on regulation and litigation will lead to a compensation and risk-averse culture	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B38 There will be a shortage of skilled public service workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B39 Changes in government policy will place more emphasis on quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B40 The use of Class A recreational drugs will be more widespread	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B41 There will be an increase in the numbers of working parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B42 There will be more fit and healthy individuals willing to devote time to volunteering activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B43 The mental health of the population will improve	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B44 There will be less expectation that young people (under 18) should be carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section C

For each of the statements below, which of the two alternatives do you think is most likely to happen in Scotland by the year 2015?

Please choose the alternative that you think is most likely to happen, not what you would like to happen.

C1. An ageing population will...

Create a massive increase in demand for statutory help and unpaid care ☐

Be fitter, more independent and increasingly provide for themselves ☐

C2. Advances in medical science will...

Help to aid recovery and thereby reduce the need for care ☐

Enable people to live longer with chronic conditions ☐

C3. The complexity of care needs will...

Increase and lead to greater demand for paid and unpaid care ☐

Be met through advances in technology and the skills of those providing care ☐

C4. An increase in single-family households will...

Lead to more unpaid care being provided by extended family, friends and neighbours ☐

Reduce the availability and readiness of people to provide unpaid care ☐

C5. Increased ethnic diversity will...

Increase the range of services that are responsive and sensitive to the needs of ethnically diverse communities ☐

Lead to greater racial tension and unmet needs ☐

C6. Technological advances will lead to...

More people in Scotland feeling isolated and lonely ☐

More flexible working and, as a result, people being able to provide greater levels of unpaid care ☐

C7. More choice and person-centred care services will lead to...

- Responsive, user-led services ☐
- Greater inequalities in service provision in favour of those with a voice and the willingness and ability to pay for better care ☐

C8. A more mixed economy of care and plurality of provision will lead to...

- Increasing quality and cost effective services ☐
- Fragmented services and greater risk that more vulnerable citizens will fall into the gaps ☐

Thank you very much for your help. Please return the completed questionnaire to OPM in the pre-paid envelope provided, as soon as possible, but **no later than Friday 8 April 2005**.

An example of the result of the use of this survey methodology (a Delphi survey) and its use as a futures planning tool (Acting Now for Tomorrow's Scotland: the future for public services 2012) can be found at:

www.opm.co.uk/scottishcarers/papers.htm

If you have any queries regarding this survey please contact Pauline Kariuki on 020 7239 0883 or pkariuki@opm.co.uk

Annex D: List of participants on 26 August

Surname	First Name	Title	Organisation
Allen	Isobel	Carer	Carers Scotland
Anderson	Ann	Former carer	VOCAL
Anderson	Colin	Head of Community Care	Borders Council
Andrews	June	Director, Centre for Change and Innovation	Scottish Executive
Begley	Pat	Director	Carers Scotland
Borner	Annette		East Renfrewshire Council
Brain	Caroline	Carer	Moray Carers Project
Burgess	Robin		Scottish Leadership Foundation
Cairns	Claire	-----	PRTC Carers Centre
Chesson	Rosemary	Professor, Head of Health Services Research Group	Robert Gordon Uni
Clark	Ruth	Policy Manager	Princess Royal Trust for Carers
Collie	Fiona	-----	Carers Scotland
Corker	Ursula	Council member	Scottish Social Services Council
Coutts	Margret	Social Work Adviser	SWSPD, SE
De Souza	Val	Service Development Officer	West Lothian Council Kerr Report Implementation Group
Dornan	Brian	Policy Manager	Shared Care Scotland
Dougall	Jillian	Chief Executive	MS Society Scotland
Eglinton	Judy		Saheliya
Elsmie	Pat	Manager	Care 21 , Scottish Executive
Fischer	Seb	Project Manager	Analytical Services Unit, SE
Galilee	John	Senior Research Officer	
Hammond	Tom	Senior Planning & Development manager	Fourth Valley NHS Board
Harper	Ian	Information Officer	National Schizophrenia Fellowship
Haslett	Julie	Project Manager	Care 21 , Scottish Executive Community Care Standing Committee
Hunter	George	Convenor	Waverly Care
Johnson	David	Director	Community care policy, Community Care 1, SE
Kerr	Brenda		Highland Carers Project
Kimantas	Pauline		

Knox	Pauline	Carer	Moray Carers Project
Lindars	Helen	Head of Policy Young Carers Network	Equal Opportunities Commission
McDonald	Louise	Officer	PRTC
Moore	Joyce	Strategy Officer	West Dumbartonshire Council
Moore	Isobel	-----	
Neill	Sean	Economic Advisor	Health Economics, Health Dept, SE
Nolan	Janet	Lecturer	EUROFAMCARE
Nolan, Professor	Mike	Project Leader	EUROFAMCARE
Paterson	Catherine	Carer	
Petch	Alison	Professor	Community Care, Glasgow Uni Community Care 2, Health Dept, SE
Philips	Douglas	Executive Officer	21st Century Social Work Review SE
Proctor	Michael		
Reid	Andrew	Independent Consultant Head of Community Care Division	Community Care 2, SE Policy for Carers, Scottish Executive
Rennie	Adam		
Robertson	Morag	Policy Officer Project Manager Race Equality	NHS Greater Glasgow
Shariff	Imran	-----	Lanarkshire NHS
Shorter	Bob		
Sim	Andrew	Policy Officer	Age Concern
Smith	Euan	Assistant Statistician	Analytical Services Unit, SE Policy for Carers, Scottish Executive
Stapleton	Peter	Head of Branch	Health & Social care, Open University Scotland
Statham	Joyce	-----	
Stevenson	Lori	-----	Alzheimer Scotland Information & Analytical Services, SE
Storrie	Ian	Economic Advisor	South Lanarkshire Council
Thompson	Suzanne	Strategic Services Manager	Joint Improvement Team Social Work Services Policy Division, SE
Torrance	Elaine	Assistant Director	
Vincent	Kate	Head of Division	Voluntary Services
Wells	Jan	Carer	Equal Opportunities Commission Scotland
Wilkes	John	-----	
Williams	Colin	former Director	Princess Royal Trust for Carers

Appendix 2:

Review of research and international case studies

Executive summary

Section One – Introduction and overview

Policy context

- The cornerstone of Scottish care policy is the *Strategy for Carers in Scotland* (1999). This highlights the vital contribution made by informal carers and seeks to ensure that there is a continuing national commitment to supporting carers' needs.
- Alongside this strategy there are several significant legislative developments within Scotland, including the 2002 Community Care Act, which helped to ensure that carers are adequately recognised and supported by Scottish local authorities and social services, and the 2001 Regulation of Care Act, which established the Care Commission and set in place the legislative framework for the development and monitoring of national care standards.
- There is also a well-developed policy network encompassing a range of governmental and non-governmental organisations, including the Joint Carers Group, national carer's organisations and Care 21.

Overview and analysis of the existing research base

- Approaches to researching informal care vary greatly. However, the following strands can be defined:
 - Quantitative research describing the state of informal care at a macro-level.
 - Qualitative research based on the experiences of a small number of carers. This is used for a variety of purposes, including: explaining the care experiences of individual groups of carers; achieving a better understanding of a particular issue that affects carers across the board; and providing an insight into what carers feel to be important.
 - Research that models future trends in informal care.
- The area of work that tends to adopt an inter-disciplinary approach to research methodology most consistently is best described as prescriptive. That is, pieces set out, or seek to set out, policies or things that need to be done for the benefit of informal carers or the care system.

Major issues in the literature on informal care

- A set of recurring issues or debates arise within the literature on informal care. For the purposes of this work, four major areas have been identified:
 - **Demographics** – analysing both the demographic outcomes of care and the demographic influences upon it.
 - **Economics** – the cost of informal care to the economy (including questions of opportunity cost and loss of productivity); the benefit of informal care to the economy; the costs of informal care on the individual; and the impact of caring on economic behaviour at the individual level.

- **The experience of caring** – the largest volume of literature, which looks at issues including the economic impacts of caring upon the individual; what the effects of being a carer are (including physical and mental health impacts); and the differential impact of caring on people from different backgrounds.
- **Supporting carers** – how carers can be supported, encouraged and helped to overcome the difficulties that have been identified.

A typology of carers

- A typology of carers is, essentially, a system of classifying the population of carers by certain characteristics that are held to be relevant to studying them.
- The intention of deriving a typology of carers from the literature is to understand the characteristics that are important in influencing outcomes for carers.
- Developing a typology of carers from the literature is an extremely difficult process, and it is fair to say that there are almost as many apparent typologies of carers as there are studies of them.
- However, there is a clear distinction within the literature as to defining the group of carers to be studied by either the characteristics of the carer, or the characteristics of the caree.
- Further relevant sub-classifications are the relationship between the carer and the caree; the ethnicity or sociological descriptors of carer and caree; the age or condition of the caree; and finally the age, gender, and economic situation of the carer, as well as the intensity of his or her care giving.

Section Two – Modelling informal care

Drivers of change in informal care in Scotland

- In recent years, much discussion has taken place about projected increases in the number and proportion of elderly people in the UK population over the coming decades. Forecasts also point towards a decrease in the number of people of working age to each elderly person in the population.
- It would appear, then, that an increasing and ageing population is likely to be one of the main drivers of change in informal care, since demand for long-term care, of which informal is one part, is greatest amongst the elderly.
- However, the relationship between age and demand for long-term care is more complicated than it seems at first, since it is the effect of age on disability and dependency levels (in terms of the ability to perform daily tasks) which actually determines requirements for long-term care.
- The issue then is the relationship between mortality and morbidity rates. There are two main competing views: that the years of morbidity will become ever more ‘compressed’ into the later years of a fixed life span; and that medical advances will lead to greater life expectancy but not be able to delay the onset of disability, so disability levels will rise.
- Other potentially significant drivers of informal care include: migration; family dispersion; the proportion of females and persons of late middle-age in the population; marital status; family structure; household composition; the age at which women first choose to have children; and

female participation in the labour market (although the weight of evidence suggests that the last of these does *not* impact on the propensity of females to provide care).

Review of the modelling literature

- This section reviews a number of models of long-term care that have involved projections of the demand and supply of informal care. Whilst the focus is on informal care, some attention is also given to modelling issues around formal care, in order to understand the relationship between the two.
- Five main models of long-term care (and one report) are discussed:
 - Institute of Actuaries model – the first attempt in the UK to build a sophisticated model of long-term care. This arrived at a figure of £33.9 billion for the total value of informal care in the UK in 1991, and the scenarios developed suggested that informal care would account for 53 per cent of long-term care expenditure in 2031.
 - London Economics/IPPR model – sought to project future costs of long-term care and outline how future funding for long-term care may be improved. This model projected opportunity costs of £20.3 billion for informal care in 2031.
 - House of Commons Health Committee Report – found that there was a consensus view that demand for long-term care is likely to increase in the future, although not unsustainably in terms of the ability to finance these projected increases. The report was also ‘very sceptical’ about some of the projections in existing models.
 - PSSRU model – made projections of the demand for long-term care for the elderly, implications for expenditure and the impact of different policies on long-term care finance, but did not attempt to put a monetary value on the informal sector. Importantly, the authors argued that demand for, and supply of, informal care are intertwined and cannot be thought of as independent.
 - US microsimulation models – where forecasts of population characteristics and behaviour are carried out at the individual level. Population-wide characteristics and formal care requirements are inferred from a sample.
 - Cass model – investigates future demand for, and supply of, informal care. Estimated that the number of elderly people receiving informal care would increase by approximately 36 per cent to 3.0 million in 2031; while supply will increase steadily from around 5 million in 2001 to about 5.3 million in 2031. As a consequence, this model did not foresee a shortage of supply before 2030. The value of the informal sector was estimated to be around £32 billion in 2000.

Section Three – Major issues in informal care

Supporting carers

- Carer breaks are felt to have the potential to alleviate some of the negative effects of caring, thereby helping to ensure long-term continuity of care. However, some commentators express concern about the negative effect on the caree, and the fact that benefits are relatively short-lived.
- ‘Carer-blind’ services: one argument is that services should never be restricted because there is informal care provision, on the basis that by providing better services to the caree, you are

indirectly helping the carer, decreasing the level of dependency. The major downside is the cost involved in increasing services, especially in the context of the limited budgets held by formal services.

- Supportive interventions: in broad terms these are schemes within which carers are provided with support groups or workers, thus reducing isolation and the potential burden of caring.
- Carers' assessments: the impact of this entitlement is not clear-cut. On the one hand, assessments are thought to be a good idea in principle; but on the other, problems include lack of awareness and a poor fit between carers' and social services' views of the support needed.
- Carer-friendly employment policies: research suggests that as many as half of non-working carers have had to give up work in order to fulfil their care duties. Changes that have the potential to allow carers to continue their careers include greater flexibility, and recognition in the workplace of the distinct needs of carers.
- Direct payments provide a range of benefits, including greater control over provision and the ability to effectively manage support. However, minor concerns centring on administration difficulties and lack of awareness are also noted.

The impact of informal care on the economy

- Macro-economic impact: informal care is generally recognised as extremely valuable to national economies, reducing the cost of state health care and producing an intangible increase in the health and welfare of the nation. There have been numerous attempts to quantify the market replacement value of informal care, ranging from (for Scotland) £200 million to £5 billion. This wide range indicates the uncertainty involved in the calculations, and the question of the opportunity cost of informal care is even more fraught with difficulties.
- Individual level: the literature suggests that the economic impact at the individual level is extremely significant; for example, research suggests that more than half of carers have incomes in the bottom two-fifths of relative income. Attempts have also been made to identify the differential impact of caring on different types of carers (e.g. men and women) but these are contentious.

Policy solutions

- Enabling carers to continue in employment is felt to be vital for their personal and social well-being, and is also supported by a strong business case. The most important measures identified include formal flexibility and informal support, and a recognition that caring responsibilities are qualitatively different from childcare responsibilities. Cultural change within organisations, perhaps based around formal training for managers and staff, is felt to be necessary in many cases.
- Ensuring that public bodies recognise and meet the needs of carers is thought to be vital. This process involves several stages: identifying and reaching carers in the first instance; diagnosing their needs appropriately; and ensuring that interactions between informal carers and formal health care providers (the 'care interface') are well managed. As noted earlier, direct payments are also felt to be very beneficial.
- Supporting young carers – there is a growing recognition that young carers have been under researched and under supported, and that this group is the hardest to identify and reach.

Even defining young carers is not easy. There is also a strong consensus that caring presents significant educational and development problems for young people. There is less agreement on whether a holistic (whole family) approach or one targeted specifically at the young carer in question is preferential.

- Caring for the mental and physical health of carers: research suggests that people providing high levels of care are twice as likely to suffer from ill health as non-carers. Aside from immediate physical health problems, carers are also more likely to suffer from depression, stress and other mental health difficulties. Solutions to these problems already adopted, or suggested in the literature, include integrating health needs assessment into carers' assessments, and other interventions such as carer breaks and direct payments.

Section Four – Conclusions

The literature is generally strong and contains a growing amount of useful work looking at the full range of informal care issues. Gaps do remain, however. In particular, young carers are under researched and approaches to researching them suggest potential difficulties. There is also a lack of research into the social value of caring and the social capital costs that it produces. The work on the economic impact of informal care is generally strong, but displays potential difficulties in methodology and data sources. There is also a clear weakness in so far as there is no agreed or robust approach to modelling the value of informal care. In general, the literature can be seen to be a good base from which to develop further work.

Section One – Introduction and overview

1.1 Introduction

The review of research and the international case studies are intended to support and inform the project, as a starting point for developing typologies and constructing ideas. They are not intended as an exhaustive academic piece, but as a study drawing out the major strands of research to provide a foundation for the study and a wellspring for ideas and innovation. The review has been produced jointly between OPM and Experian in order to draw on the expertise and knowledge of both organisations.

The material utilised and reviewed is drawn from a range of areas, most notably: academic journals and studies; governmental research, documents and work; and studies, position papers and policy briefs produced by the voluntary and private sectors. We adopted this approach because informal care is a live policy issue and an ongoing economic, charitable and social concern, and as such it is important to understand and incorporate the views of a range of experts and stakeholders.

The study is broken down into three major sections. The first, **Section One**, discusses the literature itself, analyses the forces and drivers involved in informal care, explains the different approaches taken to researching informal care, identifies the major issues and debates within the literature and then discusses the typology of carers suggested by the literature reviewed.

The second part, **Section Two**, comes from the work undertaken by Experian, and comprises an overview of the modelling literature and research into the forces and drivers affecting informal care.

Finally, **Section Three** identifies and discusses three major topics for detailed consideration. They are: supporting carers; the economic impact of informal care; and the policy response. These three topics have been chosen because they are particularly relevant to the project and the modelling of the future it involves.

This document also contains a set of five international case studies, produced as a means of understanding the care situation in other countries. These countries have been selected as representative of very different care traditions and political systems, and are intended to inform the development process.

1.2 The policy context

Understanding the policy context surrounding informal care in Scotland is an important precursor to understanding the literature. The cornerstone of Scottish care policy is the *Strategy for Carers in Scotland* (1999), which highlights the vital contribution made by informal carers and ensures that there continues to be a national commitment to supporting carers' needs, bringing carers and carers groups in to the policy process at both local and national levels and making local authorities accountable to the Executive for their plans and actions. The strategy specifically

targets young carers and provides a commitment to providing greater levels of training on carers' needs for those who work in local authorities, social services and the NHS.

As a result of, or in harmony with, this strategy, there have been several significant legislative developments within Scotland. The 2002 Community Care and Health Act was an important step forward in ensuring that carers are adequately recognised and supported by local authorities and social services. The definition of carers as those providing or intending to provide 'a substantial amount of care on a regular basis' is important, because it provides a solid working definition for carers and local authorities. In particular, it may help many of those who provide care but, when asked, do not identify themselves as carers to recognise that they do count as carers and are supported by the public sector. The fact that it leaves the exact determination of the definition to local authorities means that there is an element of local flexibility that may be beneficial for local authorities trying to support carers effectively.

Perhaps most importantly, the Act provides a universal entitlement for carers to request an assessment of their needs, independent from any assessment of the dependent. Essentially, this recognises them as important in their own right, allows them to be the focus of local authority and social service support, and cements the centrality of the role of informal carers as 'co-producers' of outcomes. The legislation also extends the scope of direct payments, specifically allowing parents, guardians or carers to receive payments on behalf of the dependent, which may have a significant impact on the relationship between low income, poor health, institutional support and the ability to care.

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. The implementation of single, shared performance measures for carers' assessments, which it is intended to create, should help to ensure the effectiveness of the assessment system.

There is also a well-developed policy network that encompasses a range of governmental and non-governmental bodies. The 'Joint Futures Group' helps to shape the future of health and social care policy in Scotland, concentrating on the need to improve joint working and provide integrated provision that allows any care provider to ensure that carers and dependants receive the full range of services they require. Equally, the national carers organisations, of which there are many, are an effective lobby and help to ensure that carers are not overlooked and that their needs are recognised and met.

The creation of Care 21, a programme established by the Scottish Executive to drive innovation and change within the social services sector, helps to illustrate the thriving policy context within Scotland. Care 21 is a small team appointed by the Executive, which will work with all interested parties, including local authorities, the NHS, the regulators and the private and voluntary sectors. The aim of the programme is to create innovative solutions to social care issues through futures exercises, widespread consultation and the identification and dissemination of good practice.

1.3 Overview and analysis of the existing research base

There is a complex and colourful literature base that may be extremely useful in analysing informal care and developing future approaches to it. The themes dealt with and the approaches taken vary greatly, and suggest that informal care is both complex and difficult to research. This section of the literature review discusses the existing research base to identify some of the key themes and debates that arise within the literature.

The literature suggests a wide range of characteristics that will be important in developing a useful typology of carers from which the research can proceed. The final part of this section discusses these characteristics, to inform the development of a pragmatic working typology that provides clearer insights into informal care and the factors that are important to carers.

Approaches

Approaches to researching informal care vary greatly and reflect both the nebulous nature of the subject matter and the wide range of issues that arise around informal care. However, three strands can be identified.

First, there is a large amount of quantitative research describing the state of informal care at a macro-level. Many of the reports, including the Carers National Association (2002), Maher and Green (2002) and George (2001), adopt a quantitative approach in order to describe the demographics of care within the UK.

Secondly, there is a large amount of qualitative research, utilising small-scale research, focus groups and in-depth studies of a few carers' experiences (see for instance Mckeand [2004] or Katbamna et al. [2004]).

The qualitative approach is used for different reasons. Some of the pieces utilise qualitative approaches to isolate and explain the care experiences of individual groups within the umbrella of carers. Katbamna et al. (2004) interviewed a small sample of carers of Southern Asian descent in order to identify and explain the specific issues facing caregivers within the Southern Asian community, something that would have been impossible to achieve with quantitative data. The Princess Royal Trust (1998) used a range of qualitative approaches to gather information on the experiences of caring within a particular region of Scotland, to analyse how communities provided care.

Others make use of qualitative methods to isolate and understand a particular issue as it affects carers across the board. Wiles (2003) focuses his piece on the relationship between informal caregivers and formal care, through a small set of in-depth interviews.

Another reason to use qualitative approaches is to describe the experiences of caregivers and provide an insight into what is important to them and how they see the situation of informal care giving. These pieces of work aim not only to describe but also to draw out elements that can inform future policy and research in a way that quantitative data will not. Aberg et al. (2004) not only describe the views of caregivers on the role they are fulfilling, but extract from that an important element of the psychological impact of care giving that needs to be recognised and addressed in future thinking. Cheung and Hocking (2004) utilised qualitative research

methodologies to describe the psychological experiences of spousal caregivers, in order to inform policy and support development.

Thirdly, there is a significant and growing literature base seeking to model future trends in informal care. This is fully discussed and considered in Section Two.

Researchers choose methods suited to their rationale for conducting the research. If the research is aimed at describing informal care, or some aspect of it, it is possible to adopt either a qualitative or a quantitative approach (contrast Maher and Green [2002] with Crompton et al. [2003]). If, however, the research addresses the experiences of carers, as with Cheung and Hocking, then obviously a qualitative approach is required. By contrast, it would be extremely difficult, if not impossible, to carry out the sort of trend analysis that Hirst (2001) undertakes without utilising a quantitative approach.

Modelling, again, requires quantitative approaches (see Packard et al. [2000] as an example). However, in cases where the author is seeking to understand the lifecycle of care or any aspect of care that is either poorly understood or largely intangible (both the Cheung and Hocking piece and the Aberg et al work are good examples of this) then the research adopts qualitative approaches in order to identify and define the issue at hand.

The area of work that tends to adopt the most consistently inter-disciplinary approach to research methodology can best be described as prescriptive – pieces that set out policies or things that need to be done for the benefit of informal carers or the care system. These pieces, such as Becker (2002) and Schwartz (2002), tend to draw upon either methodological area, or indeed both within the same piece, in order to found their arguments about policy and the future. A similar approach and trend can be seen in the work produced by the various carers' organisations such as, the National Carers Association (2002) and the report by George (2001) for Carers UK.

Major issues in the literature on informal care

The literature on informal care addresses a vast array of issues and suggests a large number of debates within the subject area. However, it is possible to discern a set of recurring issues or debates that arise within the literature, and suggest that there are some issues or areas of study that are of particular import to those conducting research or policy work in informal care. For the purposes of this work these have been broken down into four major areas: demographics, economics, the experience of caring and supporting carers. Within each of these areas certain elements consistently arise and a series of issues are repeatedly addressed.

Demographics

A large amount of the literature is concerned with describing the demographics of care and analysing both the demographic outcomes of care and the demographic influences upon it. Broadly speaking, the demographic literature consists of: descriptive pieces, such as Maher and Green (2002), which describe the demographic breakdown of informal care and its position within the national picture; trend analyses, such as Hirst (2001), which describe how informal care has evolved over time; modelling pieces such as Pickard et al (2000) and Nuttall et al. (1993) that utilise complex models and large datasets to attempt to predict the future demographics of, and trends in, informal care; and analytical pieces that use data from various sources to analyse and

describe particular characteristics of the demographics of informal caring – for instance both Heitmuller and Inglis (2004) and Carmichael and Charles (2003) analyse and describe labour force participation and pay differentials.

Economics

There is also a significant literature, some of which overlaps with the demographic literature, on the economic impact of informal care. These pieces focus on four interlinked but distinct areas: the cost of informal care to the economy, which includes questions of opportunity cost and loss of productivity, such as Carmichael and Charles (2003); the benefit of informal care to the economy, which concerns mostly the market replacement value of informal care, as in the work by Leontaridis and Bell (2001), Nuttall et al (1993) and Carers UK (2002); the costs of informal care on the individual, including lost earnings and out of pocket costs as addressed by all of the major care associations, including the Carers National Association (2002) report; and the impact of caring on economic behaviour at an individual level, which Barmby and Charles (1992) and, at a macro-economic level, Heitmuller and Inglis (2004) examine.

The experience of caring

The largest volume of literature concerns individual experiences of caring, and the way caring affects lives. Much of the work by authors such as Carmichael and Charles (2003) addresses the economic impacts of caring upon the individual, and all of the care associations have produced research and literature discussing this question. There is a raft of literature aimed at discovering what the effects of being a carer are, what issues are being neglected and how responses can be developed, for example by Cheung and Hocking (2004), Aberg et al (2004), Katbamna et al (2004), and Sawatzky and Fowler-Kerry (2003). The Strathclyde Centre for Disability Research (1999) work is a good example of an in-depth analysis of the experience of caring for a particular group of carers (young carers) in a particular locality.

There is a large literature focusing on the burdens of caring upon carers and, in particular, the physical and mental health impacts, including stress, isolation and so forth. Cheung and Hocking (2004) and Hirst (2004) pay particular attention to these questions and undertake a lot of work on the impact of caring on the individual's physical and mental health. There is also a sizeable body of literature that looks at the differential impact of caring upon people from different backgrounds. There is, for instance, literature on the impact of caring on older people (see Mooney et al. [2002]) as well as on the impact of caring on young carers (Becker [2002], Dearden [2004] and Fox [2004]). There is also a growing literature targeted specifically at examining the mental health impacts of caring, for example Cree (2002).

Supporting carers

A lot of research is concerned with how carers can be supported, encouraged and helped to overcome the difficulties that have been identified within the literature and by carers and care groups in general. Carers groups themselves, such as the Princess Royal Trust for Carers and Carers Scotland, produce a fair proportion of this literature. However, there is also a sizeable and growing body of academically produced research, for instance Phillips et al. (2001).

The literature covers a range of issues, from respite care (see Larkin and Hopcroft [1993]), to carer-blind policies (Twigg et al. [1994]) and direct payments (Carers UK [2003]). As well as the more generic support needs of carers, there is also a significant amount of literature devoted to

the specific support needs of certain groups of carers. Cree (2003) focuses on the support needs of young carers, Peacock and Forbes (2003) discuss the support needs of caregivers for those with dementia, and Stoltz et al. (2003) focus on the support needs of those caring for older people at home. Laird and Hogg (2002) heavily emphasise the information needs of carers, in terms of both knowledge about available services and publicising caring.

A typology of carers

A typology of carers is, essentially, a system of classifying the population of carers by certain characteristics that are held to be relevant to studying carers. The reason for deriving a typology of carers from the literature is to understand the characteristics that are important in influencing different outcomes for carers.

Perhaps the clearest attempt to develop a typology of carers within the literature we reviewed comes from the Princess Royal Trust (1998); this work identifies three types of carers – Immersed, Balanced and Reluctant.

Immersed carers are carers who are so involved in their care giving that they find it difficult to separate themselves from that relationship or to consider themselves independently of it. Many such carers will report not wanting help or assistance, tend to be reluctant to take a break from caring and will report that they do not miss having their own lives.

Balanced carers have intentionally organised their lives to achieve a balance between caring and living their own lives. They tend to be more proactive, willing and indeed keen to gain assistance, and to have strong ideas about how they wish to live their lives. They are generally the most engaged with formal services and the easiest for service providers to reach.

Reluctant carers are those who have had little choice in whether to undertake care giving and find it burdensome rather than rewarding. They often have poor relationships with the cared for, would not self-identify as carers, and are very unlikely to engage with formal services.

However, it is important for the purposes of this review and the wider project to develop a typology of carers that refers to other aspects of the caring relationship. Developing such a typology of carers from the literature is an extremely difficult process, and it is fair to say that there are almost as many typologies of carers as there are studies of them. In many cases the literature does not directly deal with the question of typology, but rather implies one with its approach to selecting a group of carers to study. For example, Cheung and Hocking (2004) imply a classification through their selection of spousal caregivers as a specific group that it is important to study. However, it is possible to divine from the literature certain characteristics that are central to any typology of carers and should be acknowledged when considering the issue.

First, there is a clear distinction within the literature about grouping the carers to be studied – by the characteristics of the carer or by the characteristics of the caree. Pieces like Fox (2004) define the group of carers to be studied by the fact that they are young, without reference to the people for whom they care. Others, such as Stoltz et al (2004), define the group of carers to be studied by reference to the people for whom they provide care. The literature suggests that sub-classifying groups of carers in this way allows for the isolation and examination of important elements of caring.

The reasons for adopting such distinctions are varied and complex, but a couple of examples help to illustrate the reasoning for sample selection. Fox (2004) selects his subjects by reference to the age of carers, because it is his assertion that care giving has an impact upon young people that is different to that on older people. For the purposes of examining that issue, the characteristics of the caree are irrelevant. By contrast, Peacock and Forbes (2003) have chosen to study carers who are providing care for those with dementia, because they believe the condition itself places particular strains on caregivers that are in some way unique, regardless of the characteristics of the carers.

The next stage of deciding on the typology of carers involves determining sub-classifications of either the carer or the caree. The characteristics used to classify carees are somewhat simpler than those used to classify carers. Simply put, carees tend to be characterised by reference to age or condition. It can almost be argued that they are only ever characterised by their condition, because classification by age is generally another classification of condition. So the clearest classification by age is the elderly; there is a raft of literature discussing informal care and the elderly. However, in these cases 'being elderly' is essentially the condition for which they are requiring care.

The logic seems to be that much of the impact of informal caring is shared, irrespective of the nature of the caree; but where there are differential impacts they occur as a result of the condition of the caree. The strength of this logic is best illustrated by reference to conditions such as dementia (as with Peacock and Forbes [2003]), because there are specific characteristics of the condition that affect the carer, particularly the psychological impact of carees forgetting their names and acting in ways entirely out of keeping with their previous personality, and having to watch the caree deteriorate mentally.

Where the literature characterises carees by reference to other factors it generally only does so when it is also characterising the carers by the same factor. So, for example, Katbamna et al (2004) define both carers and carees within their work by reference to ethnicity. The other clear example is when both are defined by their relationship; with Cheung and Hocking (2004), both groups are defined by the spousal relationship.

The sub-classification of carers tends to be slightly more complex. Carers are often defined by reference to age or the condition for which they are providing care, with age being of particular importance within the literature. There is a raft of literature focusing on young carers (see for instance Cree [2003]) and an equally large body of literature looking at caring in mid-life, as that age band represents the greatest concentration of carers (see Mooney et al [2002] for instance). It seems that those involved with researching informal care believe age to be one of the most significant characteristics of carers, partially because of the differential effects caring has at different ages, but also because of the differential demographics across the age groups.

Gender is the most common classification after age: a large body of work seeks to isolate and examine carers by reference to gender and through comparisons of the differential impact of caring on men and women. Barmby and Charles (1992), Spiess and Schneider (2003) and Gross et al. (2003) all define the substance of their research by reference to the gender of the carers.

There seem to be several factors at play here. First, women have traditionally been seen as the main caregivers, and indeed still constitute the majority of caregivers, hence the literature has concentrated on issues of gender to understand this situation and to track the changes in it. Secondly, economics is a major issue, with much of the literature that distinguishes between

genders focusing on the economics of informal care. This literature examines not only the differential impact of care giving on the economic positions of men and women, but also the impact of economics on whether the individual provides care and, when they do, how much care they provide.

Economics is also used on its own to classify informal carers. Most obviously, there is a body of work that classifies carers as in or out of employment. The Carers in Employment Report (1995) concentrates entirely on employed carers and the support available to them. This level of classification, in or out of employment, tends to be as far as the sub-division by economics goes, because the literature examines the effects of caring upon the economic situation of carers rather than how it may differentially affect carers from different economic situations. Much of the economic research suggests that caring affects employment decisions and the ability of individuals to maintain full time employment.

Classification by reference to the characteristics of the carer tends to become complex when researchers begin to attempt classification by multiple characteristics. The consideration of young carers, for instance, will tend to become complicated because the authors will begin to distinguish between young carers providing care for different types of condition, or within different socio-familial relationships (Dearden and Becker [2002] being a particular example).

These classifications tend to be less obvious because they generally occur within the literature after some consideration of issues, rather than as the headline classifications within. So, Spiess and Schneider (2003) classify carers by gender and hours worked, in order to examine the interactions between the two factors. There is also much discussion of the intensity of caring as an important characteristic of the caregiver, particularly as a secondary classification set against other characteristics such as gender, age or economic status. Classification by characteristics of the caree tends not to involve such multiple classifications.

In summary, the **typology of carers** consists of the following classifications:

- Relationship between the carer and the caree
- Ethnicity or sociological descriptors of carer and caree
- The characteristics of the caree:
 - condition
 - age
- Characteristics of the carer:
 - age
 - gender
 - economic situation
 - intensity of care giving.

Caring in Scotland

As with the rest of the UK, information on unpaid care in Scotland has, for a long time, been patchy and limited. In recent years, the public sector and many of the private and voluntary care organisations have sought to overcome this information deficit by carrying out research work describing and analysing the nature of unpaid care in Scotland. This work has provided a range of facts about caring that help to illuminate the situation, and a depth of analysis of the nature of

experiences of caring in Scotland that is invaluable in seeking to find ways of supporting unpaid carers. However, the amount of information available remains limited and knowledge of caring in Scotland, as in the rest of the UK, is rather fragmented.

There are 668,200 informal carers in Scotland (Scottish Household Survey 2001-2002), which means one in every eight people is caring at any one time, and 503,000 (Scottish Community Care Statistics 2002) of those are providing care to people living outside of their own homes. Sixty per cent of carers are women (Carers UK [2001]), and 75% provide care for elderly relatives (Scottish Executive [2002]); around 50% of these are caring for someone over the age of 75. For the first time, much is known about the intensity of caring relationships: roughly one in four carers is providing more than 50 hours of care each week (Carers UK [2001]). Perhaps more worryingly, there is no clear figure for the number of people under the age of 16 who are providing care: estimates range from 4,000 (Scottish Community Care Statistics 2002) to 17,000 (Carers UK [2001]). The exact value of caring to the economy is a contested question, but one recent report estimates that unpaid care saves the Scottish taxpayer £4.3 billion a year (Lothian Anti-Poverty Alliance [2004]).

Beyond the headline figures, much has been done to study the nature of caring in Scotland and to chart the experiences of people providing care. However, most of the qualitative work is area specific, and there seems to be little that attempts to study caring across the nation. This research does give an excellent insight into caring within Scottish communities and a depth of understanding that is not possible to acquire through the more quantitative national research.

The Princess Royal Trust (1998) examined the ways in which Scottish communities care by looking at a range of different communities in the Highlands. It seems from this work that there are a range of informal support networks in Scotland, but that experiences of the type and level of support available vary greatly across communities. However, the report concluded that there is no clear correlation between the nature of the community and the way in which carers and those being cared for are, or are not, supported. Rather, it seems, access to informal support is related to issues such as:

- Prior relations with the community
- The community's perception of the condition of the individual being cared for
- The carer's willingness to accept help
- The acceptability of outside help to the cared for.

Overwhelmingly, support is family based and relies heavily on the proximity of family members. Interestingly, the stability of the population is a key determining factor in whether or not strong support networks exist. The greater the population turnover, the less likely it is that individuals will be connected to an informal support network. This sort of information gives a strong understanding of the nature of unpaid care in the communities of Scotland.

Crossroads (2001) carried out an interesting study into the numbers of hidden carers within the Mid Argyll, Kintyre, Islay and Jura areas. They found that respondents to their survey identifying themselves as carers were three times more likely to be women than men; that over half lived with the person being cared for; and that 88% were caring for a relative. Over half of respondents were caring for someone over the age of 65. Those who responded to the survey tended to have very high caring workloads, and yet the vast majority (some two-thirds) reported that the person

being cared for had never had a needs assessment, and almost nine out of ten reported they had not had a carers assessment.

A study carried out by the Perth and Kinross Carers centre (McKeand [2004]) illustrates that hidden young carers are also a significant feature of the picture of caring in Scotland. The research found 199 people who identified themselves as young carers, of whom only 15 were identified through a professional and so likely to be receiving support. This suggests that the vast majority of all young carers are unknown to services and probably receiving no formal support. As their contact with services and voluntary organisations is limited or non-existent, it is impossible to tell how many young carers are receiving informal support and from whom they are receiving it.

Work in Edinburgh presented by Cree (2002) paints a rather worrying picture of young carers in the Scottish capital. According to that research, 51% of young carers lived in a lone parent family and 67% had siblings. 41% reported caring for a parent and 13% for a sibling, with the rest caring for more than one person, generally a mix of family members. 87% of those surveyed reported having provided care for a substantial amount of time. The impact of caring on the young people is particularly worrying. The study suggests that young carers have higher rates of mental health and behavioural problems, with 60% reporting difficulty sleeping, for instance. One-third reported having self-harmed and slightly over one-third had contemplated suicide. However the report is, by its own admission, unable to separate out the effects of being young and the effects of being a carer.

The picture of caring in Scotland seems to fit with many of the patterns of caring seen throughout the UK. A significant number of carers are unknown to services, are receiving no formal support and, in many cases, are struggling to find informal support. Many are suffering mental health and general health problems, many have had to give up work (see Lothian Anti-Poverty Alliance [2004] for example) and half of all carers fall within the bottom two-fifths of relative income (ibid.). A large proportion of carers are providing very high levels of care, and most are caring for a relative.

Section Two – Modelling informal care

2.1 Drivers of change in informal care in Scotland

This section discusses the likely drivers of levels of informal care in Scotland. We refer to models of long-term care described in detail in the Literature Review and other sources. Although most drivers are common to all the models in the Literature Review, some models attach greater importance to specific drivers (implied), and how certain drivers work to affect informal care can differ between models.

In recent years, much discussion has taken place about projected increases in the number and proportion of elderly people in the UK population over the coming decades. Forecasts also point towards a decrease in the number of people of working age to each elderly person in the population. Tables 1 and 2 show population figures and shares by broad age band (those of working age, dependants under 16 and the elderly population) in 2004 and 2014. Graph 1 shows annual growth rates of the same age bands.

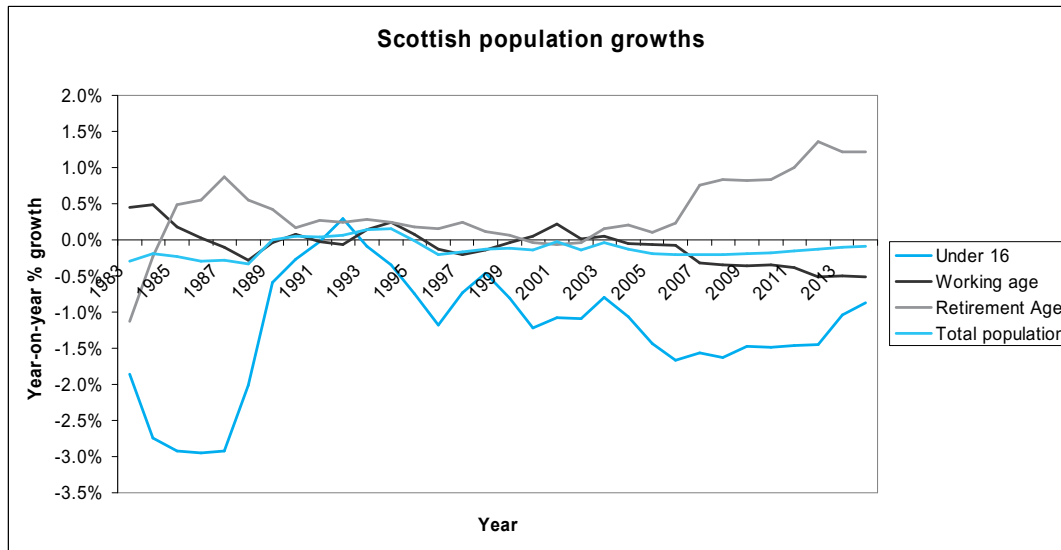
Table 1. Scottish population figures by broad age band (000s)

	Under 16	Working Age	Retirement Age
2004	642.4	3,151.0	1,253.7
2014	557.5	3,045.0	1,362.6

Table 2. Shares of total population by broad age band

	Under 16	Working Age	Retirement Age
2004	12.7%	62.4%	24.8%
2014	11.2%	61.3%	27.4%

Graph 1



As can be seen from Tables 1 and 2, growth in the dependant population is entirely driven by elderly population growth, since the number of under-16s is forecast to fall between 2004 and 2014. The proportion of the population that is elderly increases from 24.8% to 27.4% in the ten years to 2014, whilst the proportion of working age decreases from 62.4% to 61.3%.

Graph 1 shows the trend for growth in the retired population, going back almost 20 years to 1985 and expected to continue throughout the forecast period. Growth in the under-16 population has been negative for at least 20 years, except for one year in 1992. Coupled with the slightly negative growth in the total population since the early 1980s, which is expected to continue to at least 2014, this results in the shift towards an older population seen in Tables 1 and 2.

Much has been made of the implications of these demographic trends for pensions and future health care costs. It would appear also that an increasing and ageing population is likely to be one of the main drivers of change in informal care, since demand for long-term care, of which informal care is one part, is greatest amongst the elderly.

The relationship between age and demand for long-term care is however more complicated than it seems at first, since it is the effect of age on disability and dependency levels (in terms of the ability to perform daily tasks) which actually determines requirements for long-term care. As people approach and pass into old age, the chances of suffering from a long-term disability requiring care increase. If Scotland were to see a substantial shift in the proportion of people in the upper age-bands (implying greater longevity), but disability/dependency rates do not significantly change, then the impact on long-term and informal care requirement rates is also unlikely to be significant. Thus, the extent to which an ageing population leads to a higher demand for long-term care depends on *future* changes to the relationship between age and disability/dependency. The issue is the relationship between mortality and morbidity rates. This issue connects demographic factors to more technology-related drivers of care.

There are two competing views about mortality and morbidity rates. Fries (1980) put forward the view that medical advances will in the future delay the onset of disability, while life expectancy

will not increase significantly – based on the assumption that there is a biological limit to the life span of people. Future life expectancy will be around 85 years, with the years of morbidity ever more ‘compressed’ into the later years of a fixed life span. The opposite view is that medical advances will lead to greater life expectancy but will not be able to delay the onset of disability, so disability levels will rise as increased life expectancy associated with an ageing population means there are more people living to the ages where disability takes hold.

The models of long-term care that have been looked at in this study have generally taken as their central assumption that increasing life expectancy will lead to more years spent disabled.

Migration may be a significant driver of informal care, in that movement into and out of Scotland could contribute to the changing level and structure of the population. As family members move geographically further away from one another, it is possible that provision of informal care to dependants by other family members could fall, as it becomes more difficult to visit elderly parents/relatives.

Family dispersion can be considered a supply-side effect, in that it affects the potential supply of informal care. Assuming that the supply of informal care determines, or partially determines, the actual level of informal care, then we may identify a number of other drivers. For example, studies have shown that the likelihood of being a carer is highest for females and people in late middle-age. Demographic trends in the proportion of females and persons of late middle-age in the population may therefore be drivers of change in informal care.

Three closely connected supply-side drivers of informal care are marital status, family structure and household composition. A significant proportion of informal care is provided by spouses, so changes in marriage and divorce rates could therefore impact upon the availability and level of informal care. Children or close relatives of dependants also play an important role in providing care, particularly when the dependant has difficulties with personal care tasks. If couples in the future decide to have fewer children, this is likely to reduce the network of family ties and may reduce the potential supply of informal care. Trends in family structure will be linked to those for marital status.

Supply of informal care is also driven by household composition, measured in terms of whether dependants live alone or with others if single, or with other people as well as their spouse if married. Studies show care is more likely to be given if people live with the person requiring long-term care. Richards et al. (1996) make the point that ‘the decline in co-residence seems likely to continue. All evidence suggests that elderly people prefer to remain in their own homes. Increasing living standards and housing supply will allow this to continue.’ This trend could therefore lead to a reduction in the potential supply and level of informal care.

Another, possibly more important, economic factor is female participation rates in the labour market. Women are significantly more likely to provide informal care. The question then is whether increased participation reduces the propensity of females to supply care or the amount of care time given. The weight of the evidence seems to suggest that the answer is no. The House of Commons Health Committee (1996b) report ‘there is evidence that caring activity by women has actually grown, alongside their increasing participation in the labour market.’ Richards et al. (1996) reviewing previous work on the subject found ‘women co-resident workers work a similar number of hours to other women...most studies suggest a level of care is not incompatible with work.’

Trends in the age at which women first choose to have children are also likely to affect informal care supply. Women choosing to bear children later on in life may be restricted in the amount of care they are able to provide to parents, who will more likely be at an age when care is required (since the decision to have children has been delayed).

2.2 Review of the modelling literature

There is a large and growing body of literature that seeks to model future trends in informal care from the point of view of demographics and service provision. In particular, much attention is paid to the future demand for informal care and the potential implications current demographic trends have for the provision of formal care. This can then be used to inform policy responses to the issues surrounding informal care and suggest how policy needs to adapt to cope with what is in store.

This section reviews a number of models of long-term care that have involved projections of the demand and supply of informal care. Informal care is often one component of a broader model of long-term care in the studies examined here. Whilst we focus on informal care, we also give some attention to modelling issues around formal care, to gain an understanding of how informal care fits into the wider scheme of long-term care and the relationship between formal and informal care. It is important to note that the precise definition of informal care receivers/providers is not always consistent between studies. We also discuss the methods of valuing informal care employed by the models.

Institute of Actuaries model

This was the first attempt in the UK to build a sophisticated model of long-term care. The study's objectives were to project future levels of disabled people (elderly and of all ages), and to use these to investigate expenditure on long-term care under different scenarios. Four levels of disability were considered, based on the level of care required: continuous, regular, moderate and low. The model worked by applying mortality and disability rates to push forward disability by level of severity for each age group from one year to the next.

(From Nuttall et al. 1993):

Three 'states' of existence were considered: disabled, healthy and dead. Let:

l_x^d and l_x^h be the numbers of disabled and healthy people aged x at a particular level of disability;

q_x^d and q_x^h be the mortality rate (proportion of deaths) for healthy and disabled people aged x for a certain disability level;

and i_x be the disability incidence rate (proportion of healthy people becoming disabled) for people aged x for a given disability level;

Then:
$$l_x^d = (1 - q_{x-1}^d)l_{x-1}^d + [i_{x-1}l_{x-1}^h(1 - (q_{x-1}^h/2))(1 - (q_{x-1}^d/2))] \quad (\text{Equation 1})$$

Equation 1 states that the number of disabled lives aged x at a particular disability level is equal to the number of disabled lives aged $x-1$ surviving to age x (Term 1) plus the number of healthy lives aged $x-1$ that become disabled by age x (Term 2). The assumption regarding Term 2 is that healthy lives become disabled halfway through the year (between birthdays). Thus, a healthy life must survive half the year at a survival rate of $1 - (q_x^h/2)$, become disabled (at a disability incidence rate i_x) and then survive the second half of the year as a disabled person with a survival rate of $1 - (q_x^d/2)$.

Mortality rates were calculated from Donaldson & Jagger (1984), and Booth et al. (1983). Rates of healthy and disabled lives were from the (former) Office of Population and Census Statistics (OPCS). Disability incidence rates were then derived by re-arranging Equation 1 to solve for i_x . The model was applied to 1991 historical data on disability levels to project disability by level of severity to 2001, 2011, 2021 and 2031.

The model forecast a rise of 33 per cent in the total number of disabled people of all ages between 1991 and 2031, from 6.4 million to 8.5 million people. The disabled population in 2001 was 6.6 million implying a 29 per cent increase between 2001 and 2031. Focusing just on the elderly (those over 60), the number of disabled was expected to rise from 4.5 million in 1991 and 4.6 million in 2001 to 6.8 million in 2031. Since the increase in the elderly disabled population was actually greater than the increase in the disabled population of all ages, it was noted that 'the rise in the number needing care is likely to come totally from the elderly population, and thus the focus should be on this sector' (Nuttall et al. [1993]).

To measure the value of the informal sector in 1991, the study imposed a value of £7 per hour on informal care, taken from the average cost of local authority formal care. Taking the UK-wide number of informal care givers in 1991 implied by the 1985 General Household Survey, a figure of £33.9 billion was arrived at for the total value of informal care in the UK. Informal care was thus estimated to account for 77 per cent of the value of long-term care in the base year, given Laing's (1993) estimates of the value of institutional care and homecare at £7 billion and £3.1 billion respectively in 1991.

Projected (and base 1991) number of care hours were found by assuming values for the average number of care hours required for persons with different levels of disabilities. With the value of informal care set equal to the average cost of formal care provision – at £7 per hour – projected values of long-term care (formal and informal) were then calculated by multiplying this £7 figure by the number of projected care hours by disability level, and summing through all disability levels. The informal-formal split was then determined by assumptions on the proportion of the total value of care going to informal and formal care at different disability levels in the future. The study considered two scenarios to reflect possible constraints to the level of informal supply in the future:

1) 'Informal care will maintain its share of non-continuous care, but all the increase in continuous care will have to be met from the other two sectors. Thus informal care will increase by around 25% over the next 40 years.'

Under this scenario informal care made up 66 per cent of long-term care expenditure in 2031.

2) 'Informal care will not be able to increase its provision at all. This is rather pessimistic, but may be taken as reflecting overall static supply in this area.'

Under this scenario informal care accounted for 53 per cent of long-term care expenditure in 2031.

London Economics/IPPR model

This model, commissioned by IPPR, was developed by London Economics. The objectives were to project future costs of long-term care and how future funding for long-term care might be improved. As its starting point, the model employed the Institute of Actuaries' methodology (described above) to project the number of disabled people by disability level to 2031. This gave the 'physical demand for long-term care'.

An assumption was then made that informal care is universally preferred to formal care by receivers and providers. Thus, all informal carers are utilised and informal care provision is determined by the supply of informal carers. Whatever demand is left over not satisfied by informal care is then allocated to formal care. Put simply, informal care is 'first choice' for all disabled people; only when informal care supply is exhausted do people turn to formal care. Effectively, the level of informal care in the model is supply-driven. The authors qualified this assumption with three observations:

- 1) 'Both carers and dependents often prefer that care be provided by someone the dependent knows; this might be identified as a quality dimension to informal care.'
- 2) 'An element of kinship and family responsibility make informal care a duty or even an obligation for many families, reinforcing it as a first preference.'
- 3) 'For many the cost of formal care is prohibitive. The consequence of not providing informal care is that formal care will take its place. This will need to be funded by the dependent or the dependent's family (unless the dependent qualifies for means-tested assistance). This represents a major financial incentive to make informal care the preferred choice.'

Estimates of future numbers of carers were therefore required. The 1990 General Household Survey data at the individual level was used in a statistical model to estimate the probability that different types of people are carers. Probabilities were estimated for people by age, sex, economic status, household type and income. Separate forecasts were then made of population by the same level of disaggregation, which when applied to the corresponding carer probabilities gave the number of informal carers by type. Finally, informal care hours were calculated by applying the relevant average hours of care to each type of carer. Future levels of informal care, as determined by the supply of informal care, were thus projected to be:

Table 1. Informal carers and hours of care (re-produced from Richards et al. 1996)

	1995	2001	2011	2021	2031
Number of carers (000s)	7,000	7,200	7,500	7,600	7,600
Number of hours (millions)	5,500	5,600	5,800	5,900	5,900

The LE/IPPR model valued the amount of informal care by estimating the opportunity cost to carers of time spent caring; that is, the value to carers of the activities they would have been engaged in if they hadn't been providing informal care. Two types of opportunity costs were measured: waged and unwaged. Waged costs were calculated by taking projected numbers of informal carers by age, sex etc. and then applying participation rates from the General Household Survey and average earnings from the New Earnings survey to arrive at an estimate of the total value of carers' work-time if they had not been carers. The value of carers' actual work-time was then subtracted to give an estimate of the value of the 'lost' work-time.

Unwaged costs were derived by first subtracting the number of hours informal carers would have worked from the number of care hours, to give what was referred to by the authors as 'residual' hours. This is time left over and not spent working if all informal carers had switched to become non-carers. The residual was treated as 'lost' leisure time and valued at £2.50 per hour – the average cost of household help. The London Economics/IPPR estimates for the value of the informal sector between 1991 and 2031 are shown in Table 2 below:

Table 2. Opportunity costs of informal care (£ billion)

	1995	2001	2011	2021	2031
Waged	6.4	7.2	8.0	7.9	9.3
Non-waged	11.3	11.3	11.4	11.7	11.0
Total	17.7	18.5	19.4	19.6	20.3

House of Commons Health Committee Report

As part of its report on long-term care, the Health Committee looked at a number of projections of long-term care costs in the future, including those made by the Institute of Actuaries and London Economics/IPPR (House of Commons Health Committee 1996b). The Report also described projections by Laing (1993) and Whynes (1995), which broadly speaking took population projections and applied present rates of disability incidence rates and/or long-term care uptake by different demographic groups to derive future long-term care usage. Also reported were expenditure projections by the Department of Health which 'made a range of projections based on different assumptions about changes in dependency levels, the extent of any increases in the real costs of long-term care, the extent to which there will be decreasing numbers of carers, and the extent to which there will be an increase in the number of elderly people able to afford their own care.'

The Report found there was a consensus view that demand for long-term care is likely to increase in the future, although not unsustainably in terms of the ability to finance these projected increases. However, the Report was 'very sceptical' about some of the projections, and questioned the validity of combining the monetary value of the informal sector with the value of the formal sector to produce a single all-encompassing figure for long-term care, as done by the Institute of Actuaries and London Economics/IPPR. The Committee also considered the valuation of informal care provision at £7 per hour, used by the Institute of Actuaries (1993) and Laing (1993), as 'excessive', even though the Institute of Actuaries actually felt the figure might actually be too conservative.

PSSRU model

The PSSRU is an inter-university research unit dedicated to research in health and social care. The model was commissioned by the Department of Health to make projections of the demand for long-term care for the elderly, implications for expenditure and the impact of different policies on long-term care finance. Perhaps heeding the concerns expressed by the House of Commons Health Committee in their report on long-term care (described above), the PSSRU model did not attempt to put a monetary value on the informal sector.

The original model, described in Wittenberg et al. (1998), is summarised below; updated versions of the model have been used to provide projections for various organisations and for different periods into the future. The model falls under the category of cell-based macro-simulation models. Broadly speaking, these work by projecting population into the future, disaggregated by characteristics significant in determining the variable(s) of interest, in this case provision of long-term care. The propensity of each group to demand long-term care is then estimated and applied to the projections to arrive at long-term care numbers.

First, the model projected population to different points in the future to 2031, disaggregated by gender and five-year age band. Office of National Statistics (ONS) population estimates for 1995 and 1996, based ONS/GAD (Government Actuary Department) projections, were used for this purpose.

Population was then split into the institutional population (those in nursing homes, residential homes and hospitals) and private households, using a combination of General Household Survey data and the IPPRU's own survey data. Institutional care (one form of formal care) is output at this stage. Demand for community-based formal care, e.g. meals on wheels, is then assumed to come entirely from the private household population.

The 1994/95 General Household Survey included an 'Elderly' section, asking each elderly person within a household whether he/she had difficulties with various 'activities of daily living' (ADL) and 'instrumental activities of daily living' (IADL), and whether he/she received help with these tasks and from whom. Individuals in private households were placed into one of four dependency groups, according to the number and range of activities they had difficulties with:

- Problems with two or more ADLs
- Problem with one ADL
- Problems with IADLs but not ADLs
- No problems with ADLs or IADLs

Together with 1994/95 GHS individual-level data on age, marital status, dependency, household type, whether informal help was received, and tenure, demand for each community-based formal care service was thus determined by the following function:

Probability of receiving formal care service = $f(\text{age, marital status, dependency, household type, if receiving informal help, tenure})$

A statistical model then estimated the probability an individual demands each community-based service for every combination of characteristics i.e. for every person type or cell. Applying these probabilities to the number people within each population cell gave demand for formal care.

From the 'Elders' section of the GHS, informal help was defined as help from a spouse, another member of the person's household, a relative outside the household or a friend or neighbour. Anyone who received help but was not dependent was excluded, that is only dependents (Groups 1-3 above) were assumed to have received informal help.

The question of who helped when an individual answered he/she had difficulties with an ADL was only asked if the individual answered he/she could not perform without help. Individuals who reported difficulties with an ADL task but could do it alone were not asked if they ever received help. The data on informal help with personal care tasks was therefore limited and not included in the analysis. Informal help with domestic tasks was modelled only.

Informal help with domestic tasks was specified as being determined by dependency and household type (married/single and living alone/with others):

Probability of informal help with domestic tasks = $f(\text{dependency, household type})$

The authors argued that, in the case of informal care, demand and supply are intertwined and cannot be thought of as independent:

'The concept of demand for informal care, however, has little meaning in practice in the absence of family or friends willing to supply such care; that is, in the absence of potential supply...what this means is that people who need care do not necessarily receive it from the informal sector, if they lack the appropriate relationships.'

Also supply of informal care, as well as being determined by factors such as employment, income and carer health, may also be affected by the type of informal care demanded:

'Whereas a wide range of sources of support are available for help with domestic tasks, help with personal care tasks usually comes from within the elderly person's own household.'

The function describing the probability of informal care was therefore interpreted as bringing together the various aspects of demand and supply to give provision of informal care or the outcome, with dependency representing some measure of demand and household type representing supply.

Through statistical modelling of the individual-level data, estimates of the probability of a person of each dependency type living in each household type receiving informal care were calculated. Future levels of informal care were then found by applying these to the population projections.

An underlying assumption of the PSSRU model is that the relationship between informal and formal care is sequential, that is informal care is determined first independently of formal care. Formal care as mentioned above is then partially determined by whether a person is receiving informal help. In this way a certain degree of substitution is assumed.

Under the 'basecase' projections, ONS population data and GAD projections were applied without modification, and projected population was broken down using 1994/95 GHS ratios. With these assumptions the model projected the population over 65 would increase from 7.7 million to 12.1 million between 1995 and 2031, an increase of 57 per cent. The number of people over 85 meanwhile was forecast to go up 79 per cent to 1.6 million over the same period. The number of informal care receivers was expected to go up by 56 per cent, from 1.7 million to 2.7 million from 1995 to 2031.

In a later study, Pickard et al. (2000) employed updated 1996-based GAD projections on marital status in the PSSRU instead of the 1992-based numbers in Wittenberg et al. (1998) to break down future population. The study projected the number of informal care receivers would go up from 1.7 million in 1996 to 2.8 million in 2031, a 63 per cent increase. The difference with Wittenberg et al. (1998) was explained by the 1996 GAD projections, leading to a higher proportion of dependent elderly persons living with others. Since a significant amount of informal care is provided by relatives living with dependents this led to the higher figure for informal care receivers seen in the Pickard (2000) projections.

As mentioned earlier, the PSSRU model does not attempt to value the informal sector.

US microsimulation models

In the USA, the Brookings Institution/Lewin-ICF and the Urban Institute have developed models of long-term care utilising what are known as 'microsimulation' techniques. The fundamental idea of microsimulation is that forecasts of population characteristics and behaviour are carried out at the individual level. Taking a sample of individuals in the base year as the starting point, the aforementioned models apply propensities for individuals to move between different states of health and to utilise different (formal) care services; these propensities varying by sex and age. At the same time propensities also simulate changes in marital status, labour force participation, income, births etc. Thus, the life-cycle of each individual in the original sample is simulated and the models arrive at a view of the state of the sample in the forecast year in terms of the characteristics and care demands of each individual still alive in the sample i.e. there is data at the individual level in the forecast year, a projected 'sample' of individuals. Population-wide characteristics and formal care requirements can then be inferred from the sample.

Cass model

Most recently, the Faculty of Actuarial Science and Statistics at Cass Business School, City of London have developed a long-term care model to investigate future demand and supply of formal and informal care (Karlsson et al. 2004). The model employed a methodology of deriving projections of disabled people developed by Rickayzen & Walsh (2002). Uptake (demand) of formal and informal care was then calculated and the implications for costs examined. Disabled people of all ages were incorporated in the model, though it was possible to analyse results for just a subset of age groups, as was done for the elderly population (over 60s).

Basing the study on data from the OPCS survey of disability (Martin et al. 1988), 10 levels of disability were modelled – in increasing severity of disability, descending from 1 to 10. Together with 'healthy' and 'dead', these formed a model with 12 states of health. It was assumed that an individual's health can drop to any level of disability from one year to the next, but can improve only one level at a time. So, for example a person with a disability severity level of 3 may fall to any level between 4 and 10, or die, the next year, but at best can only move up to level 2.

The next step was to calculate 'transition' rates for the likelihood of healthy people becoming disabled (to different degrees), mortality for each health state, and recovery up through the scale of health. Transition rates were calibrated such that when applied to OPCS disability rates for 20 year olds by level of severity, (i.e. when this population of 20 year olds is pushed forward) disability rates at higher ages for this cohort would match (as much as possible) the OPCS disability rates seen in each age group. For projections, the model looked at scenarios based around different trends in transition rates over time. The 'central' projections assumed improvements in mortality rates consistent with GAD figures over time, and also improvements in disability rates.

Next came the allocation of the projected numbers of disabled by severity and age to formal and informal care. This was achieved by estimating for a particular 'base' year the number of people receiving different forms of formal care by disability and gender, from which probabilities of receiving the various forms of care were calculated. These probabilities were then assumed to be constant over time and used to derive formal and informal care uptake for every year's profile of disability levels.

Those utilising formal care in the base year were estimated by applying to the disability projections the historical proportional uptake of formal services according to the Health Survey of England [Bajekal 2002] and the Department of Health figures. Assumptions concerning the pattern of formal and informal care by disability level then determined those receiving informal care. These assumptions were:

'Among the people receiving any domiciliary care (formal or informal), 80 per cent receive informal care only, 10 per cent receive informal and formal care and 10 per cent receive formal care only.' (Taken from Pickard et al. [2000])

'Nobody who is entirely healthy receives informal care.'

'Everybody with severe disability receives some form of care. This means that people who are not covered by any other care setting are assumed to receive informal care.' (Karlsson et al. 2004)

To project the supply of informal carers, data from the Family Resources Survey 2001 was used to calculate the proportion of informal carers in the population by age and gender. These proportions were then applied to population projections to derive future informal supply by age and gender. Figures on average care hours from the same survey were used to translate into hours the demand and supply of informal care, enabling comparison of projected demand and supply figures.

'Central' estimates from the model indicated that the number of elderly people receiving informal care would go up from around 2.2 million in 2001 to about 3.0 million in 2031, an increase of

approximately 36 per cent. Estimates of the supply of informal care meanwhile predicted a steady increase from around 5 million in 2001 to about 5.3 million in 2031, with provision of informal care hours going up from about 100 million hours to about 119 million hours over the same period. Comparing demand and supply of informal care from all ages in terms of hours, the model did not foresee a shortage of supply before 2030.

In terms of valuing the informal sector, the Cass model assumed a care requirement of 30 hours per week for each person requiring informal care (taken from the Family Resources Survey 2001) and then applied a figure of £9.05 for the value of informal care per hour (the £9.05 figure being a weighted average of the opportunity cost for non-retired carers (average earnings) and the minimum wage for retired carers, to give an estimate for the representative informal carer.) From the above, the value of the informal sector was estimated to be around £32 billion in 2000.

Section Three – Major issues in informal care

3.1 Supporting carers

As more people become aware of the important role that informal carers play and the potential impact of caring, there is a growing emphasis on support for carers. This is reflected in the literature, within which there is a large body of work that specifically considers issues surrounding the support of carers. This section will examine some of the suggestions as to how carers can and should be supported that occur within the literature.

Carer breaks

The idea of providing relief for carers so that they can have a break from their caring duties has become increasingly prominent within the literature. The National Strategy for carers (1999) includes specific discussion of the advantages of offering short-term breaks to carers, and Edinburgh city council now has a five-year strategy to develop short breaks.

The strategy argues that by supporting the independence of carers you allow them their own time to do what they want to do, such as see friends, take care of personal needs etc – what Twigg and Atkin (1994: 150) refer to as ‘the interest of the carer *per se*.’ Consequently, some of the negative effects of caring can be alleviated; providing the carer with a break from the mental strains of caring may reduce the stress and the negative psychological impacts of caring, and allowing them time to visit friends and family may alleviate potential isolation. Care breaks may also promote long-term continuity of care, by preventing the strains of caring becoming too much for the carer.

The Royal Commission on Long Term Care (1999) argued that if a person feels valued, supported and given the right incentives to care, they will continue to do so (particularly if they get to the point where they feel they can no longer cope). The benefits are twofold –there are social benefits and it avoids the cost of residential care. The use of breaks and access to support helps carers to continue their caring role.

The literature does recognise that there are both advantages and disadvantages to providing care breaks. Many carers welcome breaks from caring, and morale and the motivation to continue caring is often elevated (Care about Carers). However, such emphasis on the carer can have a negative effect on the caree. Often referred to as institutional respite care, Twigg (1992) argues breaks can cause a conflict of interest between the carer and the caree. Many people who are cared for dislike going into care institutions. As a result, the term ‘break’ is preferred over ‘respite care’, because of the negative connotations of respite care, suggesting relief from suffering.

Also, the strategy pays little attention to the carer’s financial situation, even though research highlights the strong link between caring and poverty (Hancock and Jarvis, 1994). Larkin and Hopcroft’s (1993) study of the impact of respite care concluded that respite care could significantly decrease psychological stress (hostility, anxiety, depression and obsessive compulsion). Carers were also found to have benefited from better sleep and more freedom.

However, they were unconvinced that respite care would have significant long-term benefits, concluding that such results were relatively short-lived (generally disappearing after a couple of weeks).

‘Carer blind’ services

The Royal Commission on Long-Term care concluded that ‘better services should be offered to those people who currently have a carer’ and that an important element of this is making services carer-blind. Namely, services are never restricted because there is informal care available. The idea behind the ‘carer-blind’ approach is that by providing better services to the cared for, you are indirectly helping the carer. Relieving the carer of some of the caring tasks they undertake decreases the burden of being a carer.

Again, this approach has both advantages and disadvantages. A central advantage, according to the literature, is the focus on the interests of the carer and the cared for, helping to reduce the level of dependency. McLaughlin and Glendinning (1994) also note that greater support for older people would particularly help female carers (on whom much of the burden falls), giving them the opportunity of increased labour market participation. However, the major downside of this approach is the cost involved in increasing services (Twigg and Atkin, 1994).

Pickard et al (2000) argue that, when looking at caring for the elderly, the costs involved in supporting carers (whether carer-blind or respite) are low when compared to the cost of institutional care (Pickard et al, 2000). Twigg and Atkin (1994) however, argue that one of the major problems with this approach is that formal services are severely limited by their budgets. Consequently, those who require care will be competing for services, and the existence of a carer should influence how scarce resources are allocated. There is also a question as to whether many carees would be resistant to formal services, preferring to be cared for at home by family members.

Supportive interventions

There is a significant amount of literature that considers the potential advantages of providing supportive interventions or assistance to carers. In broad terms, supportive interventions are schemes within which carers are provided with support groups or workers in order to allow them to discuss their caring role with other carers, or to provide support to each other in terms of shared chores or giving each other short periods of time away from caring (a morning or so for instance). Such supportive intervention is aimed at reducing the isolation and burden of caring.

Assessments of the effectiveness of such programmes vary. Cummings et al. (1998) looked at the effect of participating in a psycho-educational support group for early stage family caring of persons with Alzheimer’s disease. The programme contained relaxation strategies, communication techniques, information needs and coping strategies. They concluded that the programme in question, and by implication equivalent programmes, were effective in helping carers deal with the burden of care giving, decreasing levels of strain and helping caregivers to be better prepared for the care giving role.

An investigation by Stewart et al. (1998) into the effects of an intervention for family carers of stroke survivors, delivered by lay persons (peers with similar caring roles), found almost all of the caregivers benefited. In this case, home visits were made by experienced peers, who provided

guidance and information, and carers saw the visits as supportive and as helping them to feel more capable and confident. Stewart et al. (1998) found that such support was particularly good at alleviating the fears of an inability to cope or to provide sufficient care that tend to form a major part of the psychological distress than can arise from caring.

By contrast, Mohide et al. (1990) looked at the effect of a programme called the Caregiver Support Programme (CSP). The CSP was designed to reduce the burden of caring for elderly people suffering from dementia, through regular house calls, dementia and care giving education, individual assistance, and a two-hour self-help care giving support programme. However, they concluded that no significant differences were shown on three separate measures (depression, anxiety and quality of life).

Whether or not the schemes do have clear benefits in terms of outcomes for participants, there is much debate in the literature as to how much these services would be taken up. The Crossroads (2001) work found that only about one-third of carers said they would definitely use drop-in centres and more formal support set-ups. The Princess Royal Trust work (1998) on how communities care suggests that many carers would be reluctant to use more formal support or to admit they required supportive interventions. Also both Mckeand (2004) and the Crossroads (2001) work raise questions about the geography in many parts of Scotland and the practicality of delivering such support in those areas.

Carers' assessments

Under the Community Care and Health Act 2002 there is a universal entitlement for carers to request an assessment of their needs, independent from any assessment of the dependent, combined with a requirement that local authorities inform them of this right. This assessment should look at the willingness and ability of the carer to provide continuing care, and determine what support is needed to enable them to do so.

According to the literature, the impact of carers' assessments is not clear-cut. The Carers UK (2003) report entitled 'Missed Opportunities' reports a large postal survey of carers undertaken in England. The research concluded that 60% of carers felt they weren't getting all the support they needed and only 32% had received an assessment of their needs. Those that had received an assessment had mixed responses: 37% reported an increase in services provided, whilst 57% saw no change in the help they were given. Of the 57% who received no extra support, 66% reported feeling inadequately supported. The principal conclusion of the report was that assessments are a good idea where they are focused and lead to real responses to the concerns of the carer.

Banks et al. (2002) reached similar conclusions. Their report, focusing on young carers, found that carers lacked an understanding of the purpose of assessments, and that their view of the support needed was different to the views of social services. Notably, they concluded that the things carers want out of their assessments (increased information, support and counselling, practical assistance and social and recreational contacts) was in stark contrast to the views of social services, that the assessments were to identify ways in which they could assist the family, so as to remove the burden of caring from the young person.

There is relatively little literature on the impact of carers' assessments, and so it is difficult to make any clear judgement. The pieces reviewed suggest that carers' assessments are good but more is needed to ensure that they focus effectively on what the carer needs, that they reach all

carers, and that local authorities and social services are willing and able to back them up with extra support. Surveys of Scottish carers that ask about assessments (Crossroads [2001] for instance) find that the vast majority have not received an assessment, suggesting that much work is needed to make assessments an effective tool.

Carer friendly employment policies

There is a large and growing body of literature concerning carer friendly employment policies. According to the Carers National Association (2002) 50% of non-working carers have had to give up work in order to fulfil their care duties. Mooney et al. (2002) and several other pieces have concluded that carers give up employment not because their care duties make the time commitment impossible but that the stress, exhaustion and mental health problems caused by juggling both are simply too great to bear. They conclude that were employment policies made more carer-friendly and were carers in employment better supported to overcome their difficulties many carers could be helped to continue both caring and employment.

The study by Kemp and Rosenthal (2000), cited by Phillips et al. (2001) found that being employed limited the connection between the carer and the positive consequences of caring, and that being an employed carer was linked with greater negative psychological consequences. They concluded that being a working carer leads to a conflict of roles which creates a set of negative outcomes that tend to be greater than if caring is undertaken alone.

According to the carers in employment report (1995), half of all carers surveyed who had given up work reported that more flexible working arrangements would have allowed them to continue in both roles. That report suggests that recognition and flexibility are the essential elements of carer-friendly policies. Having a policy in place that formally recognises carers allows individuals to feel more open about caring. Providing information and guidance or providing access to such services and fostering an environment within which caring duties are respected helps the carer to feel comfortable and able to cope with both roles, rather than isolated and unable to continue working. In terms of flexibility, that report suggests that allowing short-notice time off for emergencies is as important as allowing for carer breaks, and that allowing flexible hours and working from home can go a long way towards ensuring carers are able to fulfil both roles.

However, although such policies are generally agreed to help carers in employment, work by Crompton et al (2003) argues that employees still feel that caring commitments are detrimental to their careers. In particular, they feel that working shorter hours, or even working flexibly, will inhibit their prospects of promotion to higher positions, irrespective of what company policy says. Heitmuller and Inglis' (2004) findings support this conclusion. They found that carers had a lower gradient pay curve than non-carers – essentially that caring tended to limit the progress of wage increases. Equally, Crompton et al (2003) concluded that, though employees appreciated carer and family friendly policies, many felt unable to take advantage of them because it would inhibit their ability to fulfil their jobs and put added pressure on their colleagues.

Phillips et al (2001) found that employers have generally responded by helping people on an individual basis. Whilst this is admirable, it causes problems by making people feel isolated, that they are seen as putting less into the company than their colleagues and that it will inhibit their promotion prospects. Interestingly, they found that where firms were developing policies and support schemes, they were generally doing so in-house, without the support of local authorities

or social services. Their suggestion is that more effective support could be developed if it involved partnering with other bodies.

The general conclusions of the literature are that employer support for working carers, particularly when undertaken in partnership with voluntary or public sector groups, is an extremely effective means of supporting carers. It can allow carers to remain in employment, overcome some of the stress and social isolation often associated with caring, and help employers to retain experienced staff who also need to undertake certain care duties.

Direct payments

Direct payments have been the subject of a growing body of literature since their introduction. Essentially they involve the local authority paying money directly to service users or their carers, so that they can commission the services they need. The literature generally agrees that direct payments provide a range of benefits to service users and their carers. Stainton and Boyce (2004) report that direct payments allow carers greater control over provision and the ability to manage support effectively. Spandler (2004) points to a wealth of research suggesting that the increased control afforded by direct payments allows carers and carees alike to arrange their lives more to their liking and gives them greater opportunities for socialisation. Williams et al. (2003) concluded that direct payments empowered families with children suffering from intellectual disabilities, improving their care for the child and family relationships.

However, the literature is not exclusively positive about direct payments. Though generally supportive of the potential of the scheme, Dawson (2000) suggests that administration difficulties can make it difficult for users and carers to manage the system effectively. Brandon and Maglajlic (2000) found that service users were generally unaware of the direct payment system, what it could be used for and how they could access it. Clarke and Spafford (2001) concluded that direct payments had both a good and a bad side for informal carers. They found that in over half of the cases in which direct payments were received, they were managed by the informal carer rather than the user, and that they provided significant benefits in terms of allowing a more tailored use of respite and sitting services. This flexibility could help to relieve stress, increase social opportunities and lessen the burden on informal carers. Significantly, those included in the study felt that these advantages would help them to continue their care-giving role in the longer term. The note of caution they inject into their conclusions is that it sometimes seemed the system was benefiting the carer more than the user. Furthermore, Ridley and Jones (2001) found that the administration of direct payments was difficult for local authorities, and consequently the implementation of such systems was slow and had not yet spread to half of the authorities within Scotland.

The overall impression from the literature is that direct payments are a good means of support, enabling greater control and allowing carers to alleviate some of the stress and burden associated with caring. They do, however, suffer from administrative difficulties and take-up problems associated with a lack of knowledge. The literature is generally very positive about direct payments as a means of supporting carers and carees.

3.2 The impact of informal care on the economy

There is an increased recognition within the literature, and particularly among policy-making agencies and those seeking to influence policy, that informal care has significant economic

consequences. The Audit Commission report (Pickard [2004]) states that 53% of women and 40% of men will have had at least one spell of providing care for more than 20 hours a week before they reach retirement age. The literature suggests two distinct but interlinked dimensions to the economic impact of caring: the macro-economic level and the micro, or individual, economic level.

Macro-economic impact

At the macro-economic level, the economic impact of informal care can be broken down to two major issues – the value of care to the economy, and the opportunity cost of caring responsibilities to the economy as a whole.

The literature recognises that informal care is extremely valuable to national economies, primarily because it reduces the costs of state health care and produces an intangible benefit to the health and welfare of the nation. However, informal care also involves significant opportunity costs for individuals and the economy.

The literature on the value of caring to the economy focuses almost entirely on the question of quantifying the monetary value of the care, in terms of work undertaken and reduced costs to the state health care system. These two issues come together in attempts to calculate the market replacement value of informal care. Throughout the literature, in The Royal Commission (1999) report for instance, this is seen as the metric for judging the value of care, both to the health care system and in absolute monetary terms.

Informal care is valued by estimating the cost of replacing it with formal care. The basic formula is the number of hours spent caring multiplied by the average hourly cost of a local authority employed home carer. Leontaridi and Bell (2001) used this approach to estimate that the annual replacement cost of care in Scotland would stand at £200 million.

However, this is not the end of the story: estimates of cost vary greatly. Nuttall et al. (1993), for instance, estimated the replacement cost for informal care across the UK to be £34 billion. Carers UK (2002) used an adaptation of Nuttall's model to develop an up-to-date figure for the replacement value of care, multiplying the number of carers within each age category by the average number of care hours spent by people within that category by the average cost per hour of formal care, to reach a figure of £57.37 billion across the UK. They also produced figures specific to the different countries within the UK, which placed the replacement cost for Scotland at £5 billion. This is far in excess of the figure produced by Leontaridis and Bell (2001).

These are significant discrepancies, and they arise out of the complexity and uncertainty of modelling replacement costs. The Carers UK model, unlike Leontaridis and Bell, does not cap hours of care provided at 28 per week. Also, rather than simply using the wage cost of local authority home care, they have taken an average between private and public suppliers. They also introduce further complexity into the model by attempting to place lower values on non-health care activities (shopping, cleaning etc.) in order to attempt to reflect the range of support services needed.

What these differences reflect is the tension throughout the literature between different models of costing replacement value for informal care. It is far from straightforward to determine the value of the care hours and, as the various articles recognise, to estimate the number of hours of work

that would be needed to replace informal care. The source of data is also important: Carers UK used figures from the General Household Survey rather than the Scottish Household Survey. The Royal Commission report expressly recognises the difficulties of making effective calculations, and essentially rejects the effectiveness of the existing modelling of the value of informal care.

The question of the opportunity cost of informal care is even more fraught with difficulties. The essence is to calculate the value the hours spent caring would have produced had they been spent on the general labour market, i.e. what those people could have earned had they not given up that time to undertake caring responsibilities. It is extremely difficult to calculate, and results in a model built on an even larger series of contingencies and assumptions than the market replacement model. All the authors who discussed the approach, including Leontaridi and Bell (2001), Nuttall et al. (1993), Carmichael and Charles (2003), acknowledge that it is fraught with difficulties, and that in order even to get close to a working model many issues and contingencies have to be dropped, otherwise calculation becomes impossible.

For instance, if one chooses to value the economic production foregone, a large number of assumptions about the economic behaviour of individuals is involved. Would a 62-year-old carer still be in employment, for instance? The largest group of informal carers are in the 55-65 year age range and it is impossible to quantify the inhibiting effect care has had on their career progression. Equally, women working part time earn on average 40% less per hour than men in full time employment (Leontaridi and Bell [2001]), but it is impossible to determine whether these women would be working full time were they not caring and how much of the wage discrepancy arises because of the inhibiting effect of caring. Nuttall et al. (1993) provides a more thorough discussion of this issue, but the essential point arising from the literature is that this approach is very difficult and extremely inaccurate. For pragmatic reasons, therefore, the market replacement cost is the dominant model within the literature.

However, Curtice et al. (2002) did attempt to produce an opportunity cost valuation of informal care. They divided carers into two groups: those who were currently active in the labour market and those who were not. For those active in the labour market, they utilised the average wage rate for carers, defined by sociological classification (age, gender, job type), and multiplied that by the hours of work lost to caring. They admit that they overlook issues of weighting those hours by reference to the extent to which the individual's economic behaviour may have been affected by his or her caring responsibilities.

For carers not in employment, they took the average wage rate of an equivalent individual (by age, gender and marital status), but in this case removing employment sector from the equation, and multiplied that by the hours spent caring. The figures produced suggest the average weekly opportunity cost of co-resident caring to be £456 per week on average within the Aberdeen case studies, £431 in Edinburgh and £492 in Lanarkshire. Interestingly, these figures are higher than the Leontaridis and Bell (2001) market replacement costs, which stood at £384 per week. None of the literature reviewed has attempted to produce national level figures for the opportunity cost of informal care. Carmichael and Charles (2003) does, however, attempt to place a value on the average loss of earnings for individuals across the UK, which will be discussed further in the next section.

Economic impact at the individual level

There is a vast array of literature dealing with the costs of caring at the individual level, and this body of work covers a complex set of issues. At the most basic level, there are questions of lost

earnings and career progression, and direct out-of-pocket costs of caring. However, there is also much literature devoted to issues such as the impact of caring on the propensity of individuals to participate in the labour market, and the impact of caring upon later-life economic situations (reduced savings and pensions for instance).

The literature suggests that the economic impact at the individual level is extremely significant. The Carers National Association (2002) reports that more than half of carers have incomes in the bottom two-fifths of relative income. Their research, which comprised a survey of carers known to them, goes on to state that the situation may be more problematic than that headline figure indicates. They state that 50% of carers report having to give up work in order to fulfil their caring duties and that 75% of carers report that caring costs them in excess of £5,000 per annum in costs and lost earnings.

Mooney et al (2002) take these findings slightly further, to examine the impact caring has on employment decisions. Their report, which focuses on carers in their 50's and 60's, concludes that caring has an indirect influence on labour market participation. They assert that it is not the time required to undertake caring that influences the individual's decision to reduce or entirely forego labour market participation; rather it is the effect that balancing both roles has on their personal life. They conclude that taking on the additional caring role has a detrimental impact upon their leisure time, stress levels and health. Consequently, they are forced in to making a decision about how to balance work and care, or indeed whether to balance the two. They say that this incompatibility leads to people changing their working time and accepting the negative impact on their personal economic circumstances.

Whichever mechanism is accepted as the means through which caring impacts upon economic circumstances, the literature is in general agreement that caring has a highly significant impact on earnings and labour market participation. Pickard (2004) suggests, quite simply, that as the intensity of caring increases the participation in the labour market falls; almost half of carers providing 20 hours of care a week were in some form of employment, compared to less than a third who were providing 50 hours of care a week (Pickard 2004).

Carmichael and Charles (2003) examined in detail the question of lost earnings as a result of caring responsibilities. The headline finding of their work was that significant caring responsibilities led to non-trivial losses in income; they placed the figures at an average of £1550.59 for men and £614.53 for women. Though at first glance this may seem anomalous, it should be noted that these are averages of lost earnings for individual male and female carers rather than an overall figure. Carmichael and Charles also argue that male carers lose more than female carers because average earnings and hours committed to work are generally higher for men than for women. It is an unfortunate fact of the current economic situation that, for a multitude of reasons, women tend to earn less than men.

Carmichael and Charles also found the data indicated other patterns. When care is undertaken for less than 10 hours a week, it appears to have a significant impact on the earnings of women and their propensity for participation in the labour market; however, care at a low level like this appears to have a negligible effect (less than 1%) on the earnings of men. By contrast, when care exceeds 10 hours a week the situation is reversed. Women undertaking such responsibilities suffer an average 9% reduction in income, while men undertaking equivalent duties suffer a 19% fall in earnings. The difference is significant and, though it is hard to identify the causal variables accurately, it seems likely that it is explained by inhibition of career

progression, the fact that men tend to work longer hours and the fact that more men tend to work full time.

As the authors recognise, to reach any such conclusions the modelling must be based on a series of assumptions and a complex cause and effect web that makes it impossible to determine exactly which factors are most significant. It is entirely possible that the differential impact observed in terms of average earnings is due to the inequitable underlying socio-economic situation that tends to limit wages and participation for women. In particular, the fact that more women work part time and that women working part time earn on average 40% less per hour than men working full time (as Leontaridis and Bell note) may well account for the differential impact on earnings when care duties in excess of 10 hours are considered. Evandrou (1995) observed a similar effect, namely that more intensive caring duties have a more significant impact on the earning potential of men than they do on the earning potential of women. He attributes this to a lack of part-time or flexible working options for men.

The differential impact on the earnings of men and women owes much, as Heitmuller and Inglis (2004) recognise, to the inequitable socio-economic situation that tends to produce a situation within which women are paid less than men. Equally, all the authors that consider this subject recognise that it is impossible to unbundle the impact caring may have on differential career development and educational attainment. In order to proceed with their modelling, they take as their starting point the existing socio-economic situation, with the proviso that it is difficult to extricate cause and effect in terms of differential earnings. Consequently, though the figures produced will give a higher lost earning value for the average male carer than female carer, this is unweighted for various social factors and does not reflect the difference in proportionate terms. Nor are any of the authors attempting to make statements about the relative impact upon men and women; they are attempting to model, given the current situation and a set of assumptions, the monetary impact of caring on individuals.

Perhaps the more interesting conclusion of Carmichael and Charles' work concerns the impact of caring on labour supply, or the propensity for participation in the labour market. The paper extends the calculations undertaken by Barmby and Charles (1992) to attempt to evaluate the impact of caring on male as well as female labour supply. The conclusions, reached through a complex set of calculations, are that when caring is undertaken at a significant level (in excess of 10 hours a week) there is a significant negative correlation with labour market participation (the actual numbers produced hold little or no meaning outside of the equation utilised and so are not reproduced). Below 10 hours a week, caring responsibility appears to have little or no impact on labour market participation. This conclusion suggests that extensive caring duties are extremely significant in terms of the economic impact on the individual's earnings and their propensity to participate in the labour market.

The work by Heitmuller and Inglis (2004) largely supports the findings from Carmichael and Charles' work. They conclude that carers are roughly 8% less likely to participate in the labour market than non-carers, and that caring only makes a significant impact on labour market participation and wages above a certain threshold (they focus on 20 hours a week rather than 10). Once again they observed no statistically significant difference in participation rates for male or female carers. They do however, reach some much more detailed conclusions about the impact of care on wages. They observed a significant disparity between the wages of carers and non-carers who had been in equivalent employment for the same amount of time. Their statistics suggest a much flatter wage curve for carers than non-carers, indicating that caring responsibilities detrimentally impact career and wage progression.

They also concluded that caring reduces average hourly remuneration, but interestingly it does so at a fairly homogenous rate, so that hours committed to caring (beyond the basic threshold of 20) do not affect average hourly remuneration. They also concluded that the longer caring responsibilities last, the greater the impact on average wage. They conclude that carers are systematically disadvantaged with regards to earnings. They state that individuals who forego work for caring can expect to lose between £26,000 and £33,000 per year in lost income and that employed carers can expect to earn 6% less than non-carers.

3.3 Policy solutions

The literature suggests that there are a series of issues that need to be addressed; things that need to be achieved if the policy response to the needs of informal carers is to be effective. Thankfully, the literature also puts forward an array of policies, best practice ideas and approaches for tackling the problems faced by carers. This section draws out a set of areas in which a response is needed, and discusses the innovations and policies put forward within the literature for addressing them. These are not exclusively focused on the public sector. Many of them are concerned with what employers, private providers and the public sector as a whole need to do to support carers adequately and tackle the issues surrounding informal care.

The areas suggested by the literature as in particular need of policy responses are: allowing carers to continue in employment; ensuring the needs of carers are recognised and met; supporting young carers; and caring for the mental and physical health of carers.

Enabling carers to continue in employment

Supporting working carers is central to much of the research on the way forward in supporting carers. There is a large and growing body of evidence and commentary that indicates that an increasing number of people are finding themselves unable to juggle both caring and employment, and are therefore having to give up employment. Both the Carers National Association (2002) report and the work by Mooney et al (2002) clearly state that this is the case, and there is a whole raft of other work in support of such conclusions (Pickard [2004] contains a good summary of such research).

The literature is in agreement that it is important for all concerned that carers get enough support to make it possible for them to balance both work and caring responsibilities. From the perspective of carers it is important economically: the Carers National Association report (2002) states that up to 50% of carers providing significant amounts of care have had to give up work in order to continue caring; the Equal Opportunities Commission (2004) reports that caring can result in lost earnings and a carer pay gap. The bottom line that emerges from the research is that caring often means people have to reduce their working hours or forego employment completely, and consequently they face missing out on career and job opportunities and having to cope with lower incomes. They also face a particularly difficult time in building up savings and pensions to secure their future.

Beyond the economics, the inability to continue working is a social and personal problem for carers. Mooney et al (2002) report that most carers who report giving up employment in order to care state that it is not the hours involved that prevent them working, but the stress and

psychological difficulties associated with balancing the two. Furthermore, The National Carers Strategy (1999) states that working is important to carers as a means of maintaining self-esteem, for keeping an external focus and sense of satisfaction and for maintaining social networks. If carers feel unable to remain employed whilst caring it can severely affect their personal and social lives. It seems to be the virtually unanimous conclusion of the literature that enabling carers to continue in employment is important for their personal and social well-being.

The literature appears to support the National Strategy for Carers (1999) conclusion that there is a clear business case for supporting working carers. The Carers in Employment report (1995) concludes that, with the growing numbers of people providing care, and the fact that the peak age range for care provision is between 45 and 64, it will soon be essential for employers to enable carers to continue working. They add that the costs of recruitment, retraining and loss of productivity involved in losing employees, particularly experienced employees as carers are likely to be, are high, and far outweigh the costs of providing support to working carers.

Government also has reasons to help carers to continue in employment. First and foremost, the research suggests that the government is less likely to have to provide extensive financial assistance to carers because they will have their own income. By logical extension from the Carers National Association work (2002), more carers would be able to save money and develop pensions that will prevent them needing extra support in years to come. It also means that more carers will be able to maintain their care duties, so there will be fewer people in need of formal care. With the models, see for instance Pickard et al. (2000), all suggesting that the need for informal care is going to rise rapidly whilst the numbers of people available to provide it fall, there is an obvious need to enable as many people as possible to undertake care duties.

What support do carers need to enable them to juggle caring and working? The Carers in Employment report (1995) concludes that flexibility is the essence of carers' requirements. They need the ability to work more flexible hours or to work from home, to work reduced hours, to have time off at short notice for emergencies and to take breaks from employment without adversely affecting their future opportunities. The report further concludes that time off for emergencies is the most significant, followed by flexible working and working from home. Pickard (2004) reports that, in addition to these policies, carers need free access to telephones in private, so they can reassure themselves that their caree is OK; the ability to leave promptly at the end of the day; and acceptance that they may have to attend hospital appointments (and other such occurrences) during the day.

Phillips et al. (2002) concludes that, as well as formal support, informal support at work is essential if carers are to remain in employment and, importantly, overcome the limited take-up and effectiveness of formal policies. They state that supportive and understanding managers and colleagues who have a good recognition and understanding of the needs of carers are important to the carer feeling secure enough within their employment to undertake their care duties effectively.

A number of organisations have policies aimed at supporting carers, but the literature suggests that these have had only limited success so far. The problems are: many carers are unaware what is available (Carers In Employment [1995]); carers tend to prefer to use more mainstream policies, because carer support policies are often difficult to access and they fear being labelled as in need of support (Pickard [2004]); carers fear that utilising such mechanisms will still be detrimental to their careers (Crompton et al. [2003]); and doing so will inhibit carers' ability to do their job and will place added pressures on their colleagues (Crompton et al [2003]).

Much of the literature points to the same underlying problem with current policies aimed at enabling carers to continue in employment; namely that policies are primarily designed for people with childcare responsibilities and so fail to address the needs of those undertaking other care responsibilities. This is the conclusion of Pickard (2004), Phillips et al. (2002), the Equal Opportunities Commission (2004), and a range of other pieces. The literature argues that childcare and eldercare (or indeed other care responsibilities) are qualitatively different and that the provisions of childcare policy and its emphasis are incompatible with the needs of informal carers. In particular, childcare responsibilities tend to be far more predictable than other care responsibilities. Consequently, the emphasis in childcare policies on flexibility, part-time working and predictable extra leave needs is inappropriate for informal care.

Pickard (2004) states that the idea that the needs of informal carers and those with childcare responsibilities are different occurs throughout the literature and is central to an effective policy response. In particular, she cites Glendenning (1992) as concluding that carers have a greater need for flexibility and the ability to remain in work than the work break mechanisms (such as maternity leave) that form the basis of childcare policies.

Effective policies to support carers in employment need to be specifically designed around the needs of carers and designed in such a way as to overcome the take-up and effectiveness issues that currently arise. The first step suggested by the literature is to explicitly state the carer focus of policies, ensuring that they are well publicised and that carers, managers and colleagues are all aware of the policies and the needs of carers (see for instance Pickard [2004] and the Carers in Employment report [1995]). In particular, Pickard (2004) stresses the need for carers to feel they have rights akin to the rights of people with childcare responsibilities. Phillips et al (2002) takes this one step further and argues that carers should have the right to ask for flexibility from employers. The literature seems to be in agreement that implicit policies do not work and that carers need to be made to feel that they are not stigmatized and will not be detrimentally affected by their care responsibilities. This requires good communication and an environment at work that recognizes the needs of carers and fosters understanding.

According to the literature, the key formal policy for supporting carers is allowing unplanned paid leave to respond to emergencies or instances of intense care-giving need (see for instance Pickard [2004]). In addition, the right to work flexibly or from home wherever possible is very important (Carers in Employment [1995]). Equally, giving carers the right to work shorter hours without detriment to their remuneration or career prospects is seen as vital to enabling carers to overcome their reluctance to utilise the flexibility that may be available (Pickard [2004]).

There is also a strong emphasis within the literature on means of overcoming the ineffectiveness and poor take-up of current policies. Both Carers in Employment (1995) and Phillips et al (2002) identify the importance of changing cultures within organisations to make them more supportive and accepting of carers' needs. Mooney et al (2002) argue, in concurrence with the Carers in Employment group, that this is going to need more than edicts and policies: it is going to need specific training for managers and staff. Phillips et al (2002) also suggest that a strong review and monitoring system to evaluate policies and their uptakes would be invaluable for policy makers and employers in ensuring policies are working. Information is also a central plank of all of the responses suggested by the research: if these policies are to be successful then carers, managers and staff all need to be made explicitly aware of what policies are in place and the rights of carers, in much the same way as they are currently aware of childcare policies and

rights. Essentially, carers need to be made as much an everyday part of the workplace as parents, so that they can feel comfortable in balancing the roles.

Pickard (2004) also mentions a different idea. She argues that services from the formal care system should support working carers, to make juggling work and care possible. She states that she can see little evidence of formal providers offering packages of support to employed carers. However, she argues that support of this kind, in the form of complex packages of care that include, for example, meals on wheels and part-time care assistants, is invaluable to working carers. More support of this kind could help to reduce the worry of caring whilst in employment, allow carers the time flexibility they need to continue working, and help them to feel supported. She concludes that good quality support services arranged around the needs of working carers are an essential ingredient in an effective policy response aimed at enabling carers to continue in employment.

Ensuring the needs of carers are recognised and met

Whatever the condition of the dependent, the socio-economic circumstances of the carer, or the policy used to respond to the needs of either, it is clear from the literature that informal carers have needs that should be recognised and met by public bodies. The first, and perhaps most important, step is recognising carers and putting in place mechanisms to diagnose their needs. The current mechanism for doing so in Scotland and the rest of the UK is the local authority assessment of need for carers. The literature contains several critiques of the current system and proposes certain changes and responses that may well be important to future policy for recognising and meeting the needs of carers. There is much in the literature about reaching and identifying carers in the first place, so that the assessment system can be brought in to action. Finally, there is discussion of ways of enabling carers to ensure their needs are met, the most obvious of which is the direct payments system.

Taking these in their chronological order within the pathway of supporting care, the first is identifying and reaching carers. As Parker and Lawton (1994) recognise, it is often difficult to identify carers in order to address their needs. Many of the pieces of research into carers recognise that there is a definite tendency for the under-reporting of caring within surveys. This is most clearly illustrated in the contrast between the responses when people are asked if they are carers and when they are asked if their behaviour fits a description of caring (providing a substantial amount of support...). Surveys that utilise descriptions of care tend to find a higher incidence of caring than those that ask about care by name (see for instance Hirst [2002]). Overcoming this barrier and ensuring that people recognise they are what the government refers to as informal carers is important.

Defining effective research methodologies and ways of engaging carers is vitally important for the future of informal care. Without robust mechanisms for recognition and engagement it will be very difficult to conduct representative research and for policy makers to be certain of getting an accurate picture of what carers need (Lister et al [2003] provides a discussion of issues related to this question). The lesson for those designing policy responses seems to be that careful planning of research and engagement, in consultation with carers and carers groups, is essential in informing policy development.

Apart from recognition, engagement and research, there is also the question of how information is produced and provided, ensuring carers know the rights they have and the services available to them. According to the Carers UK (2003) report, over half of carers who had not received an

assessment of their needs felt they did not know what their rights were and had not been informed about their right to an assessment. Clearly, information is important at the level of making contact with carers so that they can be supported. As has been discussed with reference to supporting carers in employment, information is vital to fostering a supportive environment and the take-up of support services (Carers in Employment [1995]).

This seems to hold true for support services in general. It is difficult if not impossible to ensure carers are recognised and their needs are met if they are unaware of the rights they have and the services that are available to them. Carers UK (2003) recognises that the legislation in Scotland which requires authorities to inform carers of their right to an assessment is an important step forward. However, what little research there is currently in existence about the situation in the light of these changes still suggests that knowledge and take-up is low (see Banks et al [2002]). Preston-Shoot (2003) found that carers felt dissatisfied with the information provided to them, uncertain of their rights, and unsure of the support available. Perhaps more worryingly, he found that the formal providers surveyed felt that the information was adequate. It appears there is a mismatch here, one that tends to leave carers feeling uninformed and unsupported.

The next step in the pathway is diagnosing the needs of carers. Carers' assessments are the dominant element of this part of recognising and meeting carers' needs; however, the research suggests they have been only partially successful. As has previously been discussed, within England at least, less than a third of carers had received assessments whilst almost two-thirds felt they were not receiving sufficient support. Over a half of those who were assessed said they saw no increase in services as a result, but two-thirds still felt in need of greater support (all figures drawn from Carers UK [2003]). Banks et al (2002), reporting on the Scottish situation, though admittedly focused on younger carers, found that there was a mismatch between what carers wished to receive from the assessment and the aim of the assessment from a local authority or social services viewpoint.

Preston-Shoot (2003) conducted a survey of carers, their dependants and social workers and identified some trends that suggest the assessment system needs to be improved. His work states that social workers identify far lower levels of need across the categories identified than carers or dependents do. This suggests that assessments are under-diagnosing the needs of carers and their dependents. It is perhaps telling that his research found that carers were more likely to be in agreement with dependents on their needs than social workers, and yet social workers tended to diagnose the needs of dependents very differently to the way carers would. Also, his research suggests a mismatch between what the assessors believe to be the areas of greatest need (communication, personal assistance, management of medication and family relationships) and what carers and dependents saw as the greatest areas of need (cleaning and household tasks). Though this research primarily concerns the assessment of the needs of dependents, in all cases that assessment included assessment of support needs. Work is needed to ensure that social services and carers are on the same page when it comes to assessing needs.

Information on carers' assessments is, unfortunately, limited. There simply has not been time for a large body of research to have been carried out on the impact of the assessments within the UK. Consequently it is difficult to draw conclusions about their efficacy.

The SPRU (2000) research into effective approaches for carers' assessments concluded that they made carers feel more valued and supported by services and left formal providers feeling

clearer what the carer needed from them. They did, however, note that more time is needed than is generally allowed for assessments, and that a slightly different approach to assessments would be useful. They argue that an outcome-focused approach, built upon a conceptual framework and tools developed in consultation with carers and care groups, is a stronger basis for ensuring that needs are addressed.

Whatever the approach or the positives and negatives of assessment, it seems clear that assessment is essential. With almost two-thirds of carers (Carers UK [2003]) feeling that they have insufficient support, it is important that their needs are diagnosed.

There is also a body of work concerned with the interactions between informal carers and formal health care providers and the ways in which they are failing to effectively support carers. Shooter (2004) argues that the current care interface, and in particular carers' interactions with primary and secondary care providers, are inadequate. He cites issues such as the inconsistency and turnover of medical staff who deal with carers, the lack of time devoted by medical care for discussing issues with carers and ensuring they are coping, and the inadequacy of information given by health providers to carers. He concludes that this is a problem in terms of diagnosing and meeting the needs of carers. If they are not being properly attended to during their interactions with services and are being left uninformed, not consulted on their needs and feeling unsupported, then the formal services are failing to deal with their needs. They are also missing a major opportunity for diagnosing the needs of carers and heading off potential problems.

There are several strands of response suggested to these issues. Shooter (2004) argues that more time should be set aside for carers in consultations in which a carer will be present. This would allow more effective diagnosis of needs, quicker and easier solutions to problems, increased advice and an immediate increase in the perceived levels of support. Assessments are a somewhat more difficult question. The work by Preston-Shoot (2003) argues that assessments need to be designed so as to overcome the mismatch of expectations and diagnosis between carers and social services. He also concludes that they need to be seen to be backed up by efficient and effective response. That is, unless assessments lead to noticeable changes, then carers will continue to feel unsupported. The Carers UK (2003) report backs up this judgement and argues that assessments need to deal with the fact that carers are left feeling as if nothing has changed and, in particular, overcome the information barrier that keeps the numbers receiving assessments low.

The other strand of response is somewhat oblique but does suggest a means through which social services can ensure that the needs of carers are met. The policy in question is direct payments. The literature indicates that direct payments have the potential to manage the demand for diagnosis of need and provision of appropriate support by taking it out of the hands of the public bodies and placing it in the hands of the carer (see for instance Stainton and Boyce [2004]). There is a growing body of research that suggests direct payments can be an effective means of allowing carers and their dependents to arrange their own support as they need it in ways that commissioning through social services simply can't achieve (See Spandler [2004] as an example). It effectively removes the mismatch between the carer's perceptions of their needs and the perceptions of social services. Obviously it suffers from the same knowledge problems as assessments (Brandon and Maglajlic [2000] found particularly low levels of knowledge and understanding of the direct payment system) and it suffers from more extensive administrative problems – in particular, it is often difficult for carers to manage the system (Dawson [2000]). However, it does offer one possible avenue for recognising and meeting the needs of carers.

Supporting young carers

There is a growing emphasis within the literature on studying young carers arising out of a recognition that, up until now, the issue has been under-researched and under-supported. Young carers are the hardest group of carers to identify, reach and research (see for instance Dearden and Becker [2004]). Even defining young carers is not an easy task. There are several different definitions within the literature, ranging from the most straightforward definition of young carers as those under the age of 18 providing assistance or support to a family member (Dearden and Becker [2002]), to more complex definitions that define young carers as those under 18 whose lives are restricted by excessive or inappropriate care responsibilities (Carers UK [2002]). Though there is no clear consensus on a definition for young carers, there are certain elements of the definition that are universal: in all cases they refer to people under 18 undertaking significant care tasks; they are individuals who would usually be considered to be dependents rather than carers; and their care duties extend beyond simply having a disabled or needy relative (Dearden and Becker [2002]).

Many of the problems facing research on young carers arise out of the fact that they tend to be hidden. A series of factors are suggested as contributing to these difficulties. There is a tendency for young carers and their families to be silent about the situation within the family, either out of guilt or from some feeling that such things should be kept within the family (Carers UK [2002]). Cultural and family loyalties, a distrust of services, young people not understanding that they are carers and a fear of separation all prevent the identification of young carers.

As a result of these difficulties, where figures have been produced they tend to be uncertain and vary from study to study. Estimates of the number of young carers in the UK produced from Census and household survey figures range from 19,000 to 51,000 (Walker [1996]), to 175,000 (Dearden and Becker [2004]). This contrasts with the work quoted by Becker et al (1995), which found that 212,000 carers within the 16-35 age range had been providing care before the age of 16. The picture in Scotland is equally unclear, with estimates for the number of young carers ranging from 4,000 (Scottish Community Care Statistics [2002]) to 17,000 (Carers UK [2001]). Obviously much depends on the definition of young carers adopted; whether classification is restricted according to the nature or intensity of care or whether certain care duties are sufficient to classify a young person as a carer. The figure also depends on how the research is undertaken; whether it is derived from national census data or from in-depth interviews with young people, or indeed older carers who may once have been young carers. Whatever figure is taken and however the research is carried out, the literature is in agreement that young carers are a significant and increasing demographic.

Dearden and Becker (2004) have produced a profile of respondents to their survey that is at least indicative of the demographic makeup of young carers. Those studied had an average age of 12, 56% were girls and 44% were boys, 16% were from ethnic minority communities, 56% lived within lone parent families, 18% provided care for more than 20 hours a week and 62% had provided care for more than 3 years. These were 6,000 young carers involved with young carer support projects, so it is difficult to know whether these figures are representative and, in particular, there may be factors that hide particular young carers from such support groups. The figures are, however, indicative and suggest some important findings.

One of the most significant issues in relation to young carers is raising awareness, both of the existence of young carers more generally, and among young carers that they are actually caring

and there is support available. This is the key recommendation of McKeand's (2004) work. She suggests raising awareness in schools and putting in place school-based systems to identify carers.

Providing care has significant impacts on the lives of young people, which need to be recognised and services put in place to support young carers and alleviate the negative effects of caring. There is a strong consensus within the literature that caring presents significant educational and developmental problems for young people. Becker and Dearden (2004) found that 27% of young carers of secondary school age were suffering from educational problems. One-fifth of young carers were found to be missing out on school and one-third were suffering problems such as lateness and an inability to complete homework (Carers UK [2002]). It should be noted that these figures are for children who are in contact with a young carers support project; it is likely that problems of this type are much higher among those not receiving such support.

The National Strategy for Carers (1999) also recognises that providing care leads to young people suffering at school, becoming socially isolated and lacking the proper time and support needed to develop into adulthood. Impaired education and limited educational opportunities have a significant effect on young carers (see Becker and Dearden [2002] for example). It seems logical, according to Becker and Dearden (2002), that caring also influences the eventual employment decisions of young carers, both by limiting their educational success and by influencing them to go into caring roles professionally.

There is research to suggest, as the National Strategy for Carers does, that caring influences the mental health of young carers. In particular, it can lead to isolation and feelings of difference that place major strains on the mental health of vulnerable young people (Carers National Strategy [1999]). Banks et al (2002) quote research that suggests being a young carer can even affect the physical health of young people. Cree's (2002) work provides an excellent examination of the mental health impacts of caring: one-third self harm, one-third have considered suicide and almost two-thirds have sleeping difficulties; across the board young carers report higher incidences of mental health problems. How much is down to being young, how much is down to being a carer, and how much is the interaction of the two are all unanswered questions. What is clear is that being a young carer has significant implications for the mental health of the young person.

The picture that is presented by the research is that young carers face a range of difficulties and suffer from a myriad of potential problems that are not fully described or understood, but clearly exist and are producing negative outcomes that need to be dealt with. What young people need from policy makers is slightly less clear-cut. Banks et al (2002) concluded that young carers feel they need information, counselling and support, and practical support in undertaking their duties. However, social services tend to see the situation slightly differently, believing that their role is to assist the family in such a way as to remove the burden of caring from the young person.

The Carers National Strategy (1999) concurs with the findings put forward by Banks et al (2002) and concentrates on the needs of young carers for: recognition; support in fulfilling their care duties (with an emphasis on freeing them to undertake their education); information and contact with support services; and counselling and support. Carers UK (2002) seems to be in general agreement with these needs, but places the emphasis on a holistic approach, stating that it is impossible and insufficient to provide support to the young carer without providing support to their family as a whole. The various pieces of research agree that young carers need support

from social services to overcome the impairment of their education and personal development that can arise from undertaking care duties.

The actualities of an effective policy response are, in general, far less certain. Assessments are generally accepted as an essential first step for identifying young carers and diagnosing their needs. However, currently only 18% of those surveyed had received an assessment from social services (Dearden and Becker [2004]) and there is a significant level of uncertainty within the literature as to whether the assessments system is serving young carers well or not (see Carers UK [2002] for instance). Banks et al (2002) makes a fairly comprehensive study of the literature on assessments for young people and puts forward certain conclusions from it that suggest the system is not functioning effectively.

First, as previously discussed, there is a mismatch between what young carers see as positive outcomes of assessments (support, counselling, information and recognition) and what social workers see as the intended outcome of such assessments (to find ways to remove the burden of caring). Secondly, the assessments of young carers tend to be service-led rather than needs-led. Thirdly, children face a double layer of difficulty in undergoing assessments, because they are a child dealing with an adult as well as a layperson dealing with a professional. Consequently they can be overawed and their opinions are either ineffectively conveyed or discounted. Fourthly, there is little clear evidence whether assessments are being effectively carried out, whether young carers are being treated as both an element of supporting the family and as an individual caregiver in their own right, and even how prevalent young carers' assessments are. Dearden and Becker (2004) found that only 18% of young carers in contact with young carers support projects had received assessments of their needs. The suspicion is that very few of those not in contact with young carers projects would have done so.

What can be done to make the assessment system more effective is a difficult question. The research has few answers beyond increased information provision in schools and duties, such as those introduced in Scotland, for social services to offer assessments to young carers. However, some pieces of research suggest certain changes. Carers UK (2002) conclude that only assessments that approach the needs of the young carer, the caree and the rest of the family as a symbiotic whole will be truly effective. The National Strategy for Carers (1999) concludes that it is important for the assessment of needs to focus on the parental role of parents and their ability to fulfil it as an element of assessing young carers. Banks et al (2002) say that the research they consider suggests that there is no clear consensus on the most effective approach to assessment, but that assessments that treat the young carer in isolation or that assess the needs of the dependent in isolation are much less favoured within the literature.

Assessments are, however, far from the end of the matter. Carers UK (2002) concludes with a list of actions that they feel are essential to an effective policy response for young carers. They include; increased practical, financial and emotional support for families; recognition of the right of children not to provide high levels of care; increased training for social workers, youth workers and teachers; more comprehensive assessments; and the inclusion of provision for young carers in service planning. Dearden and Becker (2002) suggest that much more is needed from schools as a means of identifying young carers and helping social services to make contact and diagnose needs. They suggest that there should be a teacher within each school with training and up to date knowledge, charged with taking responsibility for identifying and supporting young carers within the school. They also point to the need to ensure young carers are in touch with careers

advisors and support groups and that they are periodically assessed to ensure their needs continue to be met.

Banks et al (2002) found that there are a range of positions with regards to how young carers should be supported. Many pieces of research saw inter-agency cooperation and unified approaches as essential to ensuring young carers receive the support they need. They also found an emphasis in much of the research on the provision of information to young carers, to ensure they recognise they are carers and become aware of what support is available and how they can obtain it. There was also discussion of having a consistent key worker for young carers. Having someone charged with responsibility for that young carer could well provide the overview and advocacy that would ensure their needs are met on a sustained basis and make the young carer feel more supported and better connected to support services. Furthermore, Banks et al (2002) point to a wealth of research which suggests that, like adult carers, young carers need to be provided with respite services, allowing them time to do homework and attend social activities and help to relieve the stress of caring.

Becker and Dearden (2004) suggest that much more direct parenting support for disabled parents is essential. Without this support it is impossible for services to ensure that the young carer is receiving the parental support necessary for his or her development. Encouragingly, they conclude that social services are becoming increasingly good at recognising that young carers have individual needs and referring them to support projects. They also state that their surveys suggest that the overall incidence of missed education is falling, that the proportion of young carers being assessed is rising and that young carers' projects are having success providing support. However, once again their survey was of young carers in contact with support groups, and the position of those without such contact is unknown but is almost certainly worse.

There is no unified model within the literature of how young carers can be supported; there is no golden bullet for dealing with the difficulties facing young people caring for family members. However, the research strongly suggests that information is the most important factor. Ensuring young people are well informed so that they can identify the fact that they are young carers, recognise that there is support available and know who to contact and how to obtain that support underpins all proposals for supporting young carers. Teachers, social workers, youth workers and all those in regular contact with children need the same sorts of information, so that they can identify, support and advise young carers. The literature also suggests that much needs to be done to improve research into young carers (see Becker et al. [1995] for instance), and that unveiling the hidden provision of care by young people is an important step in reaching and supporting young carers.

Caring for the mental and physical health of carers

Caring has a significant impact on the physical and mental health of carers. Carers UK report that people providing high levels of care are twice as likely to suffer from ill health as non-carers, that over one-fifth of carers report being in poor health, and that almost two-thirds suffer from ill health at some point owing to worrying about caring or money troubles (Carers UK [2001]). Aside from the immediate physical health problems, the literature suggests that the mental strains placed upon carers can cause depression, stress and other mental health problems (Carers UK [2004]). The Carers UK (2004) report modelled incidents of distress caused by care giving and concluded that caregivers suffer from higher levels of distress across the board and that the levels of distress increase as the intensity of care giving rises. The National Strategy for Carers (1999) states that carers suffer from two major health problems: over half have suffered a

physical injury whilst carrying out care duties; and over half suffer from stress-related mental health problems as a result of caring. The message is that caring affects the health of carers and is a major cause of problems related to providing care. Mooney et al (2002) cite stress and the mental strains of providing care as the key determinant in carers giving up employment.

Further research into the specific mental health problems associated with caring has found that over a quarter of carers providing more than 20 hours of care a week suffer from mental health problems (such as stress) and that carers are far more likely to suffer mental health problems if they do not receive periodic respite breaks (Singleton et al [2002]). The 2001 census reported that over 300,000 carers reported themselves as being permanently sick or disabled and over 250,000 described themselves as not being in good health (Office of National Statistics [2001]).

Carers UK (2004) found that the emotional health problems associated with caring interfere with the everyday activities of carers and restrict both their social and personal lives. In many cases, carers report ill health brought on by being overly tired, having little or no time to tend to their own health and being stressed from providing round the clock care. Worryingly, many report that the problems of poor mental and physical health reduce their ability to provide care and the likelihood that they will continue to be able to provide care in the future.

Much work is needed if these health problems are to be tackled. As previously discussed, helping carers to remain in employment, thereby reducing the isolation of caring and ensuring that they have an external focus to their lives, would help tackle some of the mental health problems associated with caring (see Mooney et al [2002] for instance). Consequently, the health needs of carers cannot be extricated from policies to support carers to remain in employment.

However, the literature generally concludes that much more is needed and much more direct response to mental health needs is important if carers are to be adequately looked after. This is explicitly recognised in the Strategy for Carers in Scotland and the Carers National Strategy. As a result, the Scottish Executive has made it a requirement that all carers are given an assessment of their needs, which includes their health needs. The Carers UK work (2004) suggests this is a good step forward. However, more needs to be done. Carers UK (2004) set out an extensive list of measures that would help improve the mental and physical health of carers. Early identification and diagnosis of needs, inextricably linked with assessments, is one of those. However, they specifically stress improved access to counselling, training and support services as means of supporting carers and improving their health. Both Cummings et al (1998) and Stewart et al (1998) conclude that support programmes produce measurable improvements in the health of carers. They concluded that such programmes reduce isolation, promote a joint spirit amongst carers, reduce stress and lead to better mental and consequently physical health amongst carers.

Carers UK (2004) also goes on to state that carers need regular (annual) health checkups, that those in high-risk groups should become part of the local health needs assessment policy, and that services for disabled and elderly people should be expanded to include carers in a more active role. They also return to the question of the interface between informal carers and formal care, and state that primary care workers should take responsibility for identifying the health needs of carers they come in to contact with.

Another major area of focus within the literature is the question of carer breaks. Much of the literature, Singleton et al (2002) for instance, argues that breaks are an essential element of

protecting the mental and physical health of carers. They report a far lower incidence of mental health problems in carers receiving periodic carer breaks than in those who do not receive breaks. Twigg and Atkin (1994) argue that breaks are essential to allow carers to maintain a proper social and personal life, break the cycle of stress and burden and ensure that they do not become overwhelmed by their care duties. The Royal Commission on Long Term Care (1999) reached similar conclusions, adding that such breaks ensure the provision of informal care in the future by preventing carers from feeling that they cannot continue caring. Larkin and Hopcroft (1993) concluded that respite care could significantly decrease psychological stress, and allow better sleep and more freedom for carers.

Further to the earlier discussions of direct payments, much of the literature on that subject suggests that direct payments can help alleviate mental health problems, by empowering the carers and allowing them to arrange care and breaks as they see fit (see for instance Spandler [2004]). Consequently, carers are able to manage their own situation more effectively and, hopefully, control the mental health problems that can arise.

This is clearly an area of considerable concern within the literature and one in which there is no single clear response. However, the overall picture is that there is much that can be done to improve the mental and physical health of carers. Much of it is connected with other areas of response, and much of it seems to be almost intangible (social support networks for instance), but there are clear responses that can be made.

Section Four – Conclusions

There is a vast and growing literature focusing on informal care in Britain and throughout the world. Although this literature review does not cover all of it, it is possible to draw some conclusions as to the strengths and weaknesses of the literature, as well as any gaps that may be relevant to the project as a whole.

The literature is strong in terms of being comprehensive and robust in its coverage of the economic issues relating to informal care. Although there are gaps in certain elements of this area of research, generally a very broad range of pieces cover a lot of ground. The literature is also strong in dealing with and describing the benefits of supporting carers in employment. There is a large amount of literature dealing with the needs of carers, particularly considering the psychological and emotional impact of caring.

Equally, there is a range of literature that covers different support approaches. In particular, the literature on supportive interventions is thorough and well researched, and suggests there have been a good range of studies in this area. It is also apparent that there are certain conditions whose impact on carers is extremely well researched: dementia and cancer are the two most prominent examples.

The literature also shows a high level of coverage of the qualitative impact of informal care. A wealth of studies adopt a qualitative approach to researching informal care, in order to draw out some of the more intangible elements of caring, covering issues such as anxiety, the attitudes of carers to caring and the negative and positive impacts on the social lives of carers.

However, there are several clear weaknesses in the literature that should be noted. First, there is a lack of an accepted and robust method for determining the value of informal care. The discrepancy in estimates, which range from £250 million a year to £5 billion a year in Scotland, suggests that this is a weak element of the literature. It is a question that is of more than technical interest, because the value, or indeed the replacement cost of such care will heavily influence future care policy. There is no one approach that is accepted and as such the literature is unable to yield a robust estimate.

Secondly, the literature does not seem to include discussion of an effective and useful typology of carers. Individual pieces of research suggest one through the approach they take, but there does not appear to have been detailed discussion of which of the characteristics is influential. Certain important factors may be under- or over-represented within the literature. It is, however, difficult to pick these out without first having that debate as to the proper typology of care.

Thirdly, there are certain areas in which the literature demonstrates gaps. There is, for instance, a lack of research into issues of ethnicity and the impact of different heritages on care patterns. There is also a dearth of research into issues such as the differential situations of urban and rural carers, and the specific needs of each group. Most obviously, there is a definite lack of research, analysis or writing on the social value of caring. That is, thinking beyond economic or market replacement value and into the benefits caring brings to carers, carees and the community as a whole. There is very little research here, largely because it is a nebulous concept that is difficult

to research, but it is clearly a side of informal care that is important. There is also, in a related theme, no real research into the social capital produced by caring, or indeed the social capital foregone in order for care to be undertaken. How many people would undertake voluntary duties or become more heavily involved with political or social institutions if they were not caring?

The issue of young carers is an area of the research that has gaps and displays weaknesses. There is, clearly, a lack of research in to young carers, and though this is beginning to be remedied, the lack of research should be taken in to account when considering young carers. There is also, within the literature on young carers, certain weaknesses. There is no agreed classification of what a young carer is, or what nature and extent of care duties is required for a young person to be classified as a young carer for the purposes of research. There are also problems in identifying and reaching young carers. As the various authors note, many young carers are hidden and it is often very difficult to identify which young people are undertaking care duties and which are not. Consequently, much of the research relies upon known young carers (those currently involved with young carers programmes for instance), which is a pragmatic response to the question, but creates serious difficulties in drawing conclusions. It is likely, as an example, that carers identified in this way will be receiving support and so such research may well under-estimate the support needs of young carers. Equally, it may exclude certain groups of young carers who are more reluctant to become engaged with support groups. For example, it may be that the specific cultural pressures in the Sikh community mean that young carers in that community are less likely to be engaged with such support. There is a need for a more robust method of identifying and researching young carers.

The literature on modelling the future of informal care also displays weaknesses. Obviously, the lack of a single robust approach to valuing informal care poses immediate problems for such modelling, and so those models produce different future cost models which it is hard to reconcile. There are also, as with all future modelling projects, a series of assumptions built into the models which are crucial to their usefulness. There is not, however, any clear agreement as to what these assumptions should be, and so the models will tend to produce diverse results. This makes it difficult to utilise models of the future in order to develop policy.

There are also clear weaknesses and gaps in the literature where it focuses upon the various support policies. There is not, for instance, a large body of work analysing the impact of direct payments, and the work on carers' assessments is still in its formative stage. There is no doubt these weaknesses will be remedied, but for now they do represent gaps in the literature.

The individual economic impacts of informal care and the modelling of the differential influences of care across gender and socio-familial situation that occur within the literature also give rise to certain difficulties. It is almost impossible, for instance, to disentangle the causal influences upon the wage differential across genders. There is no means of quantifying to what extent the uneven burden of caring impacts differentially upon the educational attainment and professional success of men and women. It is also extremely difficult to make robust models of the impact of informal care on the propensity to participate within the labour market. The basic difficulty of determining how much labour market participation would have occurred without the caring duties is further complicated by the fact that the average participation rates that are generally used to draw estimates have inevitably been influenced by care duties. For instance, the average working hours of a 55 year old married woman in the UK from which researchers draw their estimates have already been influenced by the fact that a relatively high number of women of this age have care duties; it is impossible to say what those figures would look like if care duties were removed.

Inevitably, such modelling and analysis involves a variety of counter-factual thinking that makes drawing concrete conclusions problematic.

Overall, the literature is strong and much progress has been made in studying informal care and identifying the future needs of carers. Gaps and weaknesses remain and they need to be taken into account when the literature is used to inform the future of informal care and informal care policy.

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Annex: International case studies

Introduction

These case studies have been developed to further inform the current exploration of the future of unpaid care in Scotland. They are intended to highlight the ways in which different countries attempt to support carers and ensure their needs are met.

The cases have been chosen as they are one of the following: examples of good practice within a set of models relevant to the Scottish context; examples of good practice within a quite different model; or examples of good practice within a similar model.

Each of the cases is described in terms of:

- The caring situation
- The legislative and policy framework
- The support systems in place
- The outcomes
- Key links

Within these broad headings information pertaining to carers rights, political context and “hallmarks” or innovation within the systems is also highlighted.

International perspective

The latest WHO study on the numbers of people dependent on care from others suggest that there are challenges that will have to be faced in regards of Health systems, and both paid and unpaid carers.

“Large increases in the population of very disabled people are predicted for most parts of the world. This will necessitate the development of an infrastructure for health and social care with substantial capacity to support this population and their carers (...) Where large increases in the prevalence of dependency are not expected (i.e. in Europe and Japan) the proportion of severely disabled people will rise in comparison with both the total and working-age populations. Declining fertility means that there will be fewer people available either for generating wealth or for taking on professional or informal caring roles”

(Rowan H. Harwood, Avan Aihie Sayer & Miriam Hirschfield, Bulletin of the WHO “Current and future Worldwide prevalence of dependency. Its relationship to total population, and dependency ratios”, April 2004, 82 (4))

Dependency is defined as – *“the need for human help (or care) beyond that customarily required by a healthy adult. Most such help is given by family members or other “informal” careers.”*

(Rowan H. Harwood, Avan Aihie Sayer & Miriam Hirschfield, Bulletin of the WHO, “Current and future Worldwide prevalence of dependency. Its relationship to total population, and dependency ratios”, April 2004, 82 (4))

[http://whqlibdoc.who.int/bulletin/2004/Vol82-No4/bulletin_2004_82\(4\)_251-258.pdf](http://whqlibdoc.who.int/bulletin/2004/Vol82-No4/bulletin_2004_82(4)_251-258.pdf)

See also older people perspectives at http://www.who.int/gb/ebwha/pdf_files/WHA55/ea5517.pdf

Finland

What is the caring situation?

In Finland there are about 300,000 Family Care Givers who are providing care for someone who is disabled, suffering from a long term condition or an elderly relative or friend at home. About 23,000 of the carers receive Home Care Allowance from their local municipalities. The municipalities are basically responsible both for health care and provision of social services. The people have no obligation, according to law, to provide care for their disabled, long term ill or elderly relatives but many people are doing so. In Finland women as well as men are actively participating the labour market and usually as full time workers. Finland is also geographically a large country, and many adults live far away from their parents and this fact has an effect on the family care of elderly people.

http://www.omaishoitajat.com/english_info.html

What is the legislative and policy Framework?

The structure of Finnish society has been based on the Scandinavian welfare state model, where the government plays an important role in both income transfer and in organizing education, health, social, cultural, and other services. Services are mostly provided by the municipalities and income transfer is organized by state finances and statutory insurances.

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_finland_rc1_a5.pdf

In the Context of Home Care the following Acts are Important:

- The Act on Social Welfare Care, which requires municipalities to provide income support and arrange services. According to this Act, the municipalities have to organize services, for example home help services, institutional care, service housing and preventive services. The municipalities have the freedom to decide how they provide or arrange the care services. The Home Care allowance for Family carers is based on this Act.
- The Primary Health Care Act and The Specialized Health Care Act require the municipalities to organize Health care Services needed by local residents.
- The Act for Services and Assistance for Disabled Persons. The aim of this Act is to improve the ability of a disabled person to live as normally as possible and to prevent and eliminate the disadvantages caused by the disability. The Act covers all the services needed to achieve this purpose. The Act gives people diagnosed as seriously disabled the right to necessary services. This means that the municipality has to provide these services. Moreover the Act of Special Care Services gives the framework for the services of Developmentally handicapped persons. http://www.omaishoitajat.com/english_info.html

What support systems are in place?

Home Care Allowance is paid to carers who practice care at home for persons with lowered capacity, sickness, disability or other similar problems. Home care allowance is granted on the basis of a contract between the municipality and the carer. Attached to this contract is a care plan which specifies which services will be provided and by whom, this must be agreed by the municipality, the care recipient and the carer. The Home Care Allowance can be granted in the form of money, services or both. The minimum care fee is Euro 224,2 (£152) per month. The rate depends on the time and the extent of the assistance required.

In 2002 a new Act came into force, which obliges municipalities to give round-the-clock carers two free days per month. The municipality must provide substitute care during this leave but can charge a fee for it. The Home Care Allowance recipients are insured for accidents.

In some municipalities it is possible for the carers to receive a higher allowance from approximately Euro 850 (£578) up to Euro 1200 (£816) per month for giving care to persons who need institutional care but are cared for at home. http://www.omaishoitajat.com/english_info.html

Individual rights

Owing to the nature of the Social Democratic system there is no charter of rights for carers per se, rather there are a set of rights which all those who are social care clients have which apply to carers. The Ministry of Social Affairs states these as:

'In both public-sector and private-sector services, clients have the right to good-quality social welfare and good, non-discriminatory treatment. Social welfare must respect every client's human dignity, right to self-determination, beliefs and privacy.'

Social welfare should take into account clients' wishes, opinions, interests and individual needs, and their mother tongue and cultural background. Personnel are required to explain to clients not only their rights and obligations, but also the various options available and their effects in individual cases. Special attention is paid to the status and rights of those needing a great deal of care and attention, old people, the mentally handicapped and minors.'

<http://www.stm.fi/Resource.phx/eng/subj/socwe/polic/statusbrochure.htx>

Those providing care are also entitled to an allowance from their municipality which should also include employment pension accrual to ensure that caring does not adversely affect their retirement. Carers providing full time care are also entitled to two free days per month during which the municipality must make arrangements for care provision. Those giving care have the right to an assessment of sorts, which comes in the form of the drawing up of a comprehensive care plan which includes services and assistance.

What are the outcomes?

After the state subsidy reform in 1993, state contribution decreased significantly, but increased again in 2001. At the moment the municipalities have more responsibility in deciding what kind of services they offer and the criteria for the financial support, which is normally based on the dependent person's need estimated on the basis of his / her functional capacity. The municipalities have varieties of services and levels of financial support for informal care.

Presently the open care services are emphasized in social and health care and their development is in progress. The aim is to enable older people to live in their own homes for as long as possible, and often they prefer staying at home to institutional care. However, some older people will always need institutional care, especially those who are suffering from dementia or have nobody to care for them.

Families are expected to take more responsibility for their older members in need of care, but they are also provided with services arranged by municipalities. Personal care and service plans are made by a multiprofessional team for persons in continuous need of care. The family care giving is mainly supported by two different means. It is granted as funding for informal care and / or different kind of services provided by the municipality.

In Finland the selection of services for older people has been limited to light open care such as home help and home nursing a couple of times per week or heavy institutional care. In the future, the intention is to develop services more flexible and multifaceted to cover the variety of needs of older people at different stages of disability.

(National Background Report for Finland)

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_finland_rc1_a5.pdf

Key links

Association of Care Giving Relatives and Friends

<http://www.omaishoitajat.com/english.html>

National Background Report for Finland

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_finland_rc1_a5.pdf

Finnish Ministry for Social Affairs and Health

<http://www.stm.fi/Resource.phx/eng/index.htm>

Denmark

What is the caring situation?

Much like other Western European Countries Denmark has a rising amount of older people in the population. Following from this there are considerable pressures on both health and social care in the extensive Danish Public Sector.

As a general rule the Danish Welfare system is not reliant on individual willingness to care for people with disabilities, illnesses or for palliative care. This is considered to be a service that the state (or in fact local authorities) should take care of, as part of the principles of the universal welfare state and the following high rates of taxation. Services are given independently of the individual's relation to market and family relations. The systems that are in place solely support people that wish to care for someone.

http://www.sfi.dk/graphics/SFI/Pdf/Social_velfaerd/social_tryghed_i_Europa.pdf

What is the legislative and policy framework?

The overall responsibility for health care lies with the Ministry for the interior and Health. The role of the ministry is to legislate, initiate, coordinate and advise. Equally the Ministry of Social affairs are responsible for social care. However most services are devolved to authorities at the lowest possible level, so as to provide the service as close as possible to the user.

Healthcare is generally funded and controlled through the regional authorities. Social care is divided between local and regional authorities depending on the specific area. The local authorities generally pay the economic assistance to carers. In general these systems work well, but there have been some problems with pushing out cost from health care in regional authorities to social care in the local authorities. Equally the local authorities have been charged with pushing cost from social care into health care.

The Structure of local and Regional authorities are about to change though as a major structural reform is in the process of being implemented and is due to be completed 2008.

Both the state, local and regional authorities collect tax from the population to fund their activities. There is some re-imburement from the national level to local and Regional authorities. (DUT) All have elected assemblies and have the rights to levy taxes.

www.im.dk

What support systems are in place?

Care for Children with disabilities

Both parents can apply for re-imburement of their potential earnings for the period in which they care for their disabled child. This goes for re-imburement of pension as well. The size of the monthly payments depends on previous income.

Care for Close Relations

This form of "Leave" is for people that are employed, but wish to take up to 6 months off to care for someone.

The requirements are that:

- The illness or disability is a long term condition or chronic
- That the person cared for does not live in an institution already
- That the alternative to the person being cared for by the carer is that the person would otherwise need to be in an institution. Or that there is a need for care that amount to a full time job.
- That both parties – the carer and the cared for – accept the arrangement

During the leave the carer is employed by the local authority of the person cared for and is paid 16.556 dkr.(£1505) per month (2005), plus pension.

Palliative Care for terminal patients

If a carer wishes to care for a friend or family member you can get economic assistance to do so. The economic assistance is minimum 11.609 dkr. (£1050) per month (2005). The only requirement is that the local authority accepts that the carer is able to care for the relevant person and that the person cared for agrees.

Alternatively the carer can apply for re-imbursement of their potential earnings for the period in which they care for the terminal patient.

Pilot projects on parents caring for and training their brain damaged children

Under this pilot scheme parents can be employed by the local authority to care for and train their brain-damaged children in the home.

www.social.dk

Individual rights

The Danish system relies on a universal social-democratic approach to welfare which means it is geared not towards assisting carers but providing care. Consequently everyone is entitled to have their care needs met by social services and the system operates on the basis of unpaid care being the exception to the rule. As a result of this all those in need of care are entitled to whatever services are required and so the carer can avail themselves of state services in order to assist and support their caring duties.

Where individuals choose to undertake care themselves they are, subject to the aforementioned terms, entitled to support in the form of paid carer leave or payment for loss of earnings.

What are the outcomes?

In general there seem to be quite high levels of satisfaction with both Health and Social Care, which the Danish authorities provide. Because of the very limited use of these support systems, information is scarce. There do not seem to be evaluations or reports on the specific subject.

The discussion of the Danish model primarily focuses on the considerable expenses connected to the universal welfare state model. The specific area of caring for close relations, handicapped children or the terminally ill is not considered controversial. In fact measures have been set in place to ensure that parents can also be paid to care for their own healthy children.

Key links

Ministry for Social affairs

www.social.dk

Ministry for the Interior and Health

www.im.dk

Australia

What is the caring situation?

Carers Australia describe the caring situation in Australia as:

2.3 million Australians are providing care for family members or friends with a disability, mental illness, chronic condition or who are frail aged. This represents one in every five households. However because many carers are hidden this figure is regarded as an underestimate.

Nearly 20% (450,900) of all people providing assistance are primary carers, that is they provide the main source of unpaid informal support. Without carers, many people would be institutionalised and community care, as we know it would cease.

Conservative estimates show carers 'save' the economy \$16 billion (£6.4 billion) annually. Carers are the major providers of community care services, delivering 74% of all services to people needing care and support. The Home and Community Care Program, worth over \$800 million (£321 million) nationally, meets only 9% of this need.

It is recognised that many carers are among the poorest, most disadvantaged people in the community. Over one-half of all full time carers recently reported incomes of less than \$200 (£80) per week. While incomes are less, expenses usually go up and carers have to use up savings or superannuation, cut back on basic living costs or borrow money just to get by.

Key facts

- 70% of primary carers are female
- 79% of primary carers care for a person in the same household
- Care is mostly for a partner (43%), child (25%) or parent (21%)
- Most primary carers are of workforce age (78% are aged 18 to 64 yrs) and 21% (or 97,000) are aged over 65 years
- Even though the majority of primary carers are of workforce age, paid work is usually not possible. 59% are not attached to the workforce
- 69% of primary carers receive a government pension, benefit or allowance and for 56% of primary carers it is their principal source of cash income
- 40% of primary carers have been providing care for a decade or more, and 68% for more than 5 years.

Most primary carers (54%) said that they provided care either because alternative care is unavailable or too costly, or because they consider they have no choice.

<http://www.carersaustralia.com.au/index.php?option=content&task=view&id=75>

From : *Australia's Welfare 1999 Services and Assistance*, Australian Institute of Health and Welfare Caring Costs, Carers Australia 1998

Disability, Ageing and Carers: Summary of Findings, Australian Bureau of Statistics, 1998

Just as national and international awareness of the contributions made by informal carers has been growing, there has emerged a concurrent concern about the sustainability of the current patterns of informal care provision, both in terms of pressures on the supply of carers and factors likely to increase demand for care. Some observers of change in the United States have proposed that the ageing of the population will bring with it a larger proportion of the population with health and personal care needs and that this is occurring at the same time as the traditional supply of paid and unpaid caregivers is shrinking (NHPF 2002). These concerns have been shared by some Australian researchers (Schofield & Bloch 1998) who cite a range of relevant changes in the Australian context, including the shift to deinstitutionalisation of care, the growing number of women in the workforce, increased rates of relationship breakdown, and the tendency toward smaller families. The ageing of carers has also been identified as an issue of concern, particularly in relation to older parents who care for their grown children with disabilities (AIHW 2000)."

<http://www.aihw.gov.au/publications/aus/aw03/aw03-c03.pdf>

What is the legislative and policy framework?

Much of the work regarding carers in Australia is happening through the Health and Community Care Program (HACC). The HACC Program is a joint Commonwealth, State and Territory initiative. It funds basic maintenance and support services to help frail older people and younger people with disabilities continue to live in the community. The aim of the Program is to assist these groups to live at home longer. Without HACC services they may be unable to manage at home and may need to go into long term residential care (such as a nursing home).

"The Program began in 1985. In 1998, Commonwealth, State and Territory Ministers updated it to:

- make it more relevant to people's needs; and
- improve its efficiency and effectiveness.

Formal agreements between the Commonwealth, States and Territories set out the arrangements for the Program and define who is responsible for different elements of the Program. The Commonwealth, States and Territories are jointly responsible for:

- developing a national strategic plan every three years;
- agreeing individual plans for HACC services in each State and Territory;
- agreeing how much money is to be provided in total and for each region;
- sharing costs;
- developing and maintaining national policy documents and guidelines such as the *National Framework for HACC Assessment*; and
- developing program outcome indicators covering areas such as quality, appropriateness, effectiveness and costs of care, effective targeting and program efficiency.

(Summary National HACC Program Guidelines July 2002: 2)

The Commonwealth is responsible for:

- national policy initiatives; and
- identifying national trends in the HACC Program through publishing an annual statistical overview and an annual national analysis of developments.

It consults with the States and Territories on these matters.

The States and Territories are responsible for:

- developing Annual Plans;
- providing an annual Business Report to the Commonwealth;
- developing, implementing and evaluating models of assessment;
- approving and contracting service providers;
- liaising with providers;
- making available external, independent avenues for handling consumer complaints and disputes; and
- implementing state, territory and regional advisory and/or consultative mechanisms to: involve consumers and providers in policy and planning; and
- enable community feedback on services.”

http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/hacc-pub_pg_npg.htm

What support systems are in place?

The economic support system is divided into two areas. The two systems are described in the following section.

Carer payment

The Carer Payment (Adult and Child) is an income-support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments such as the Age Pension. It is set at the same rate as the Age Pension, and is subject to the same income and asset tests. As at 31 December 2002, 71,210 people were receiving Carer Payment (Centrelink unpublished data). Because the Payment is for people who cannot earn an income because of fulltime caring responsibilities, the majority of carers receiving Carer Payment are aged between 25 and 64 years. The rate is currently \$(Austr.) 92.40 (about £35) per fortnight

Carer allowance

The Carer Allowance (Adult and Child) is payable to co-resident carers who provide fulltime care on a daily basis to someone who needs substantial amounts of care because of a disability, severe medical condition or age-related frailty (limited to two adults). The Allowance can be paid to carers in receipt of a government pension or benefit, including Carer Payment. It is not income or asset tested, but eligibility is determined according to an assessment of the care recipient's care needs. The level of the Allowance, adjusted on 1 January each year, is designed to help

meet additional costs involved in caring for a person with a disability. The rates are currently: \$(Austr.) 470.70 per fortnight (£204) for single carers and \$(Austr.) 393.00 (£170) each per fortnight for couples.

[http://www.centrelink.gov.au/internet/internet.nsf/filestores/co031_0501/\\$file/co031_0501en.pdf](http://www.centrelink.gov.au/internet/internet.nsf/filestores/co031_0501/$file/co031_0501en.pdf) and <http://www.aihw.gov.au/publications/aus/aw03/aw03-c03.pdf>

These systems are funded through the Health and Community Care system (HACC).

“Prior to 1985, home-based care services in Australia were scanty and poorly coordinated. The problem had been raised in a succession of government reviews and inquiries, but gained particular prominence in a report of the House of Representatives Standing Committee on Expenditure in 1982. One consequence was the Home and Community Care (HACC) program, announced in the 1984 budget, and aimed at substantially improving the quantity and range of services available to frail and disabled older people living at home. In the years that followed, both the quantity and variety of services increased substantially. Between 1985–86 and 1991–92, expenditure on this program doubled in real terms.”

<http://www.aihw.gov.au/publications/welfare/oag/oag-c27.html>

Apart from the economic support from the HACC, The Commonwealth Carer Resource Centres in each state and territory provides carers with referrals to services and practical written information to support them in their caring role.

Care Resource Centres

Carer support groups: Carer support groups allow people of similar circumstances to get together, let off steam and relax by sharing experiences, feelings, ideas, concerns, information and problems. It is also an opportunity to have a break, socialise, learn from other carers and rejuvenate. Many groups welcome all carers while others focus on a specific disability or illness.

Community health centres: Community health centres offer a variety of services that may include child health, counselling, speech therapy, physiotherapy, community nursing and mental health.

Food services: When people have difficulty preparing their own meals at home, food services can deliver nutritious meals (fresh or frozen) to their homes or provide meals at a centre. Each service may vary in the range of support provided. People with particular dietary needs for health, religious or cultural reasons can have special meals arranged.

Home help: Home help services can assist you with practical tasks at home. Services may include house cleaning, shopping, laundry and personal care such as bathing, dressing or toileting.

Home maintenance and modification: Assistance can be provided for essential home repairs and modification. Help may include installing safety ramps and support rails, changing light globes and widening doorways. Referrals can also be made to reliable trades people for other work.

Home nursing: A trained nurse can visit people in their homes to improve or maintain their health. They may provide assistance with personal hygiene, medication, give injections or change dressings. Care can be provided regularly or occasionally when you need it.

Palliative care: Palliative care is for people with a terminal illness to relieve pain, reduce stress and aim to optimise personal dignity, independence and choices around dying. Your local hospital or community health centre can provide details of the closest palliative care service, or contact the Palliative Care Association.

Respite: Respite is a form of support for carers enabling them to attend to everyday activities and to have a break from their caring role. Respite can be given informally by friends, family, neighbours, or by formal respite services. Respite services can supply a trained person to provide support at home, called in-home respite, or at facilities such as day care centres, hostels and nursing homes. Respite can be for a few hours, days or longer periods. Respite is important for the carer's long-term health and well being. Limited financial assistance towards respite may be available in cases of emergency or one-off situations.

Transport: Transport services can assist people who are unable to use or have no access to regular transport. Transport could be to and from appointments, shopping and social activities. When you need to attend appointments at you local hospital or community health centre, transport may also be available through these services.

Volunteer programs: Volunteers carry out home visits, help with food shopping and provide transport to medical, dental and hospital appointments as well as many other services that may help carers.

Furthermore, a **national carer counselling program** was being piloted up to June 2004.

Carers are now able to access a new counselling service specifically designed to meet their needs. The Government has provided \$3.6m to fund the National Carer Counselling Program (NCCP) up to June 2004. Continuation funding will be subject to progress with the Community Care Review.

The Counselling Program provides counselling and related emotional and psychological support services for carers, in order to reduce carer stress, improve carer coping skills and facilitate continuation of the caring role.

In particular, NCCP aims to:

- provide short term counselling through professionally qualified counsellors.
- target the provision of counselling services to the specific needs of carers.
- facilitate the establishment of group counselling services for carers.
- ensure that the counselling service is well integrated with all other forms of education and support services offered to carers.

Counselling is available for such issues as:

- Stress management or crisis counselling
- Coping skills and strategies (for example, in coping with a major deterioration in the well-being of the person in care)
- Bereavement and loss for former carers on the death of the person they supported
- Transition issues relating to the person being supported moving to a residential care facility, assisted accommodation or to another primary carer in the community
- Practical problem-solving techniques.

The focus of services is on the particular needs of the individual carer in relation to the caring role, and assistance may be provided on a one-off basis or over several counselling sessions. Services can be provided in a location to suit the carer, e.g. in-home or at the counselling service. For carers in rural and remote areas, counselling may be via telephone services or face-to-face counselling through a local service provider. The possibility of Internet-based services will be explored in some areas.

The program is not intended to address deep-seated problems requiring long-term analysis or therapy for resolution.

The Counselling Service is delivered by the Commonwealth Carer Resource Centres in every State and Territory and managed by Carers Australia.

The HACC fee structure will be applied to carer counselling clients, noting that there are safeguards to allow fees to be reduced or waived in accordance with the carer's capacity to pay and fees are capped where several HACC services are being accessed.

National carer counselling program, National service delivery standards and Guidelines.

http://www.carersaustralia.com.au/documents/carers_guide_book.pdf

Individual rights

Although carers do have extensive support in Australia they tend to have few rights under Australian statutes. The health records legislation in Australia, for instance, does not give carers a right to see the medical records of the person for whom they're caring. There is also no standing right for the carer to be consulted in medical decisions relating to the person being cared for

(<http://66.102.9.104/search?q=cache:PznaDgKatLsJ:www.dhcs.act.gov.au/pubs/documents/discussion%2520paper.pdf+carers+rights+australia&hl=en#7>).

However, as has been discussed, there is an increasing amount of support for carers in Australia. They have, under the HACC system the right of access to services and the right to a carers allowance to help cover the cost of caring. Statistics suggest that around 69% of carers receive direct income support.

What are the outcomes?

Informal carers have played a pivotal role in the deinstitutionalisation of aged care and disability services, chronicled in an earlier edition of *Australia's Welfare* (AIHW 2001). The shift to caring for people with a disability in the community depends on the availability of informal carers to take on a caring role. The narratives of carers highlight that, for many, to do so is not a decision as such. For them, being a carer is a natural expression of their relationship with a family member or friend in a time of need, however long that may be. Yet studies of informal care reveal that caring at home may not always be a carer's first choice and can extend well beyond what most people might expect of family life (e.g. CAA 1999; Schofield et al. 1997). There is widespread recognition that, while caring may be rewarding, carers may also experience the stress of social isolation, physical and emotional strain, and reduced education and employment potential.

<http://www.aihw.gov.au/publications/aus/aw03/aw03-c03.pdf>

The publication yearly publication "Australia's Welfare" sets out the development of informal carers in Australia on a yearly basis. The publication concludes that provision of informal caring will increasingly depend upon people's ability to combine work and family responsibilities. A wide range of policies will be required to support carers. Family-friendly workplace policies will need to be extended to apply to people who are caring for people with a disability or frail older people, and not just to those with dependent children.

(AIHW 2003, *Australia's Welfare 2003*, Australian Institute of Health and Welfare, Canberra)

<http://www.aihw.gov.au/publications/aus/aw03/aw03-c03.pdf>

Key links

The Department for Health and Ageing

<http://www.health.gov.au/>

Carers Australia

<http://www.carersaustralia.com.au/>

AIHW 2003, *Australia's Welfare 2003*, Australian Institute of Health and Welfare, Canberra

<http://www.aihw.gov.au/publications/aus/aw03/aw03-c03.pdf>

Currently, the Australian Bureau of Statistics' Child Care Survey and Survey of Disability, Ageing and Carers are the main sources of national information. The most recent Child Care Survey was conducted in 2002 and the 5-yearly Survey of Disability, Ageing and Carers, last conducted in 1998, is in the field as at date of publication.

<http://www.abs.gov.au/>

USA

What is the caring situation?

The services provided by family caregivers represent 80% of all home care services and are conservatively valued at \$257 billion a year (approx £171 billion), more than twice the amount spent on paid home care and nursing home services combined.

More than 50 million family caregivers in this country provide care for a chronically ill or aging family member or friend. And there are at least another 10 million caring for loved ones with special needs, younger than 18.

<http://www.familycaregiving101.org/>

Overall:

- The typical caregiver is a 46-year-old Baby Boomer woman with some college education who works and spends more than 20 hours per week caring for her mother who lives nearby.
- Female caregivers provide more hours of care and provide a higher level of care than male caregivers.
- Almost seven in ten (69%) caregivers say they help one person.
- The average length of care giving is 4.3 years.
- Many caregivers fulfil multiple roles. Most caregivers are married or living with a partner (62%), and most have worked and managed care-giving responsibilities at the same time (74%).

Caregivers and work

- Almost 60% of all caregivers either work or have worked while providing care.
 - 62% have had to make adjustments to their work life, such as reporting late to work or giving up work entirely.
 - Male caregivers are more likely to be working full- or part-time than female caregivers (66% vs. 55%).

Who do caregivers care for?

- Most caregivers (89%) are helping relatives.
- Nearly 80% of care recipients are over 50 with the other 20% 18-49.
- Caregivers who help someone age 50 or older say the most common health problems the person they care for has are diabetes, cancer, and heart disease.
- One quarter of caregivers helping someone age 50 or older reports the person they care for is suffering from Alzheimer's, dementia, or other mental confusion.

Caregivers' unmet needs

- The most frequently reported unmet needs are finding time for myself (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%).
- About three in ten caregivers say they need help keeping the person they care for safe (30%) and finding easy activities to do with the person they care for (27%).
- One in five caregivers say they need help talking with doctors and other healthcare professionals (22%) or making end-of-life decisions (20%).

http://www.familycaregiving101.org/not_alone/stats.cfm

What is the legislative and policy framework?

The New Freedom Initiative Caregiver Support Workgroup was established to identify and coordinate existing caregiver support activities across agencies within the U.S. Department of Health and Human Services (HHS). The workgroup is a sub-group of the HHS New Freedom Initiative staff group that was established to respond to the President's Executive Order on Community-Based Alternatives. Several solutions outlined in the report to the President, "Delivering on the Promise," seek to enhance HHS support of family caregivers of people with disabilities of all ages. The workgroup will play a leadership role in promoting these solutions as well as coordinating overall HHS caregiver support activities.

<http://www.aoa.gov/prof/aoaprof/caregiver/careprof/proguidance/resources/CAREGIVER%20COMPENDIUM%201.3.02.pdf>

The National Family Caregiver Support Program

The enactment of the Older Americans Act Amendments of 2000 established an important new program, the National Family Caregiver Support Program (NFCSP). The program calls for all states, working in partnership with area agencies on aging and local community-service providers, to have five basic services for family caregivers. These services include:

- information to caregivers about available services;
- assistance to caregivers in gaining access to services;
- individual counselling, organization of support groups, and caregiver training to
- caregivers to assist the caregivers in making decisions and solving problems
- relating to their care giving roles;
- Respite care to enable caregivers to be temporarily relieved from their care giving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

Currently funded at \$155.2 million (approx (£100 million), this program has served more than 275 thousand caregivers nationwide. Efforts regarding NFCSP have resulted in new partnerships, improved access to services, outreach to special populations, and provision of services to respond to the unique needs of families.

http://www.aoa.gov/press/oam/May_2003/media/fact_sheets/National%20Family%20Caregiver%20Support%20Program.pdf

What support systems are in place?

Insurance

Most people - whether as patients, family caregivers, or health professionals - do not have a good idea of what medical insurance (assuming the patient has some) will pay for until the need arises. Family members and patients are often shocked to find that insurance will not pay for many services and items needed at home that are routinely paid for in the hospital. Unless the person has specific long-term care insurance (and very few people do at this point), many home care needs, especially home care aides or attendants, will not be covered at all or beyond an initial short-term period.

National Family Caregiver Support Program

Until recently, federal public policy has neither acknowledged nor supported the service needs of families in their care-giving role. The Older Americans Act (OAA) Amendments of 2000, in authorizing the creation of the National Family Caregiver Support Program (NFCSP), stands as the most significant legislative accomplishment to date on behalf of family caregivers. The NFCSP recognizes and encourages the vital role caregivers play in the country's home and community-based services, offering five categories of support for caregivers in a coordinated and responsive manner. This national program, implemented through the aging network (i.e., Administration on Aging, State Units on Aging, Area Agencies on Aging and service providers), includes the following support:

1. Information to caregivers about available services
2. Assistance to caregivers in gaining access to supportive services
3. Individual counselling, support groups and caregiver training to assist caregivers in making decisions and solving problems related to their roles
4. Respite care to temporarily relieve caregivers from their responsibilities
5. Supplemental services, on a limited basis, to complement the care provided by caregivers.

Although care giving and long-term care now command attention in Congress as well as in state legislatures, information on and analysis of caregiver support services within the context of long-term care and the new NFCSP are lacking. Little is known about states' experiences in providing caregiver support: whether in states that have well-developed systems of caregiver support services funded largely with state general revenues, or in states that have just begun to create programs through the new federal resources provided by the NFCSP.

Individual rights

Individual rights for carers vary greatly across the different states and it is almost impossible to give any concise statement as to the rights of carers. However, the rights to services they have sit far below the level of the UK and in fact any of the countries in this study. In general any formal care needed has to be covered by the individual's medical insurance and if it is not then it is left to the person or their carer to pay. Consequently there are many cases in which the responsibility for caring falls on a family member because they are unable to meet the costs involved.

The federal programmes discussed above don't create any rights for carers rather they set in place support services which carers can access if they wish.

What are the outcomes?

The NFCSP is already producing results. Preliminary data from state agencies indicate that they have exceeded statutory expectations to serve 250,000 caregivers by serving over 325,000 caregivers during the first years of implementation. The same preliminary data reflect that the states and area agencies on aging are providing a solid mix of services to caregivers, including information, assistance, counselling, respite, and supplemental services. Early data from AoA's first national survey of caregivers indicate that caregivers value the services provided by the Network to older clients. Eighty-eight percent reported that services enabled them to care longer than would otherwise have been possible, and 72% reported that the services "helped a lot." (Administration on Ageing, 2002 Annual report)

http://www.aoa.gov/about/annual_report/ar_supporting_care.pdf

The Family Caregiver Alliance has since published a review of the NFCSP. It states:
“From the lessons learned through the experiences of these 10 states, issues for the future were identified. Seven issues call for attention:

1. Family support should be an explicit objective of all federal and state long-term care policies and programs.
2. The funding level of the NFCSP must be raised to effect broad policy reform and systems change such that family caregivers are seen as true partners in long-term care.
3. To reduce fragmentation and increase quality of care, federal and state programs targeted to the elderly and to persons with disabilities need to be linked to those that target the family caregiver.
4. NFCSP reporting requirements need to address caregiver outcomes and uniform standards for caregiver assessment.
5. The NFCSP should build on state interest in exploring consumer direction in both caregiver support programs and home and community-based services.
6. States should be given more opportunities to learn about promising practices.
7. The shortage of direct care workers needs increased attention at the federal and state levels.”

(Lynn Friss Feinberg, Sandra L. Newman, Carol Van Steenberg, *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since passage of the National Family Caregiver Support Program*, 2002)

http://www.caregiver.org/caregiver/jsp/content/pdfs/op_200211_10_state_full.pdf

Key links

Key Findings from “*Care giving in the U.S.*” National Alliance for Care giving and AARP, April 2004, Funded by MetLife Foundation. <http://www.caregiving.org/04keyfindings.pdf>

Family Care giving 101. <http://www.familycaregiving101.org/>

Department of Health and Human Resources web page for caregivers.

<http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>

A Compendium of HHS Caregiver Support Activities

<http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/CAREGIVER%20COMPENDIUM%201.3.02.pdf>

Summary of Care giving Legislation in 108th Congress. Compiled by the National Alliance for Care giving and the National Family Caregivers Association, updated September 8, 2004. <http://65.36.183.181/news/CGLeg108thCongress.pdf>

Promising Practices in the US.

http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/nfcsp_projects/PromisingPractices.pdf

Current National Legislation

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=789

Federal Republic of Germany

Introduction

As a result of projected demographic and economic change, Germany shares similar challenges of future care provision with other European countries. Germany's carer-focus emerged largely through the development and introduction of a long-term care insurance (LTCI) in 1995 which for the first time gave carers formal recognition, resources and legal entitlements to training. Some of these developments, and other features, provide interesting lessons which should inform the current Care 21 debate in Scotland:

- Germany's model of federal, 'Laender' and local authority parliaments provides new devolved government structures in the UK and Scotland
- Germany is the only European country to date which has responded decisively to the national care agenda by introducing in 1995 an additional 'hypothecated' tax to fund long-term-care provision through a form of a social long-term care insurance (LTCI). (*Hypothecation = the process of earmarking tax revenues for specific purposes*)
- The introduction of LTCI in Germany has elevated the role and culture of care in German society, created a new income base for the funding of care provision, directly benefited unpaid carers and their families and has stimulated new drivers for the local care economy and employment.

The caring situation

If UK definitions of 'unpaid care' were applied to Germany, some 10 million Germans could be expected to be 'unpaid carers' in a population of 82 million, and some 4 million likely to provide 'regular and substantial care' for someone for more than 50 hours per week.

However, the country's statistical information on 'unpaid carers' or 'care-givers' is less developed than in the UK. Exact figures are only available from LTCI statistics and only include those in receipt of LTCI to whom criteria apply as defined in statute (*Pflegeversicherungsgesetz, Sozialgesetzbuch XI, 1994*).

In 1998, the German government projected an increase of people aged 60 plus from 21% of the population in 1995 to 36% by 2030 – evidence of the perceived 'explosion' of need for long-term-care services and the resulting financial burden for individuals and the state. These projections had led to the introduction of the *Soziale Pflegeversicherung* (social long-term-care insurance).

Definition

For the purposes of Germany's long-term care insurance, persons in need of long-term care are those who "owing to a physical, psychological or mental illness or disability, require a significant or major amount of help to carry out the daily and recurring routines of everyday life over a prolonged period of time, probably for a minimum period of six months."

The relevant need for assistance relates to the areas of personal care, nutrition, mobility and housekeeping. The decisive criterion in assigning a person 'statistical relevance' is the amount of time a relative or other informal carer needs to provide the necessary help with their personal care, feeding, mobility (basic care) as well as housework.

Calculated on a weekly basis, the minimum amount of time required per day must average not less than 90 minutes; of which more than 45 minutes must be accounted for by basic care.

Care statistics

On the basis of the definitions above, *Destatis (Statistisches Bundesamt Deutschland)* identified just over 2 million Germans in need of care and in receipt of LTCI in December 2001. Of these 69% were women; 81% over the age of 65 and 35% 85 years or older.

1.44 million (70%) of those in receipt of LTCI were cared for at home, approx 1 million exclusively by unpaid carers, and 435,000 (30%) lived in residential care homes.

Statistics also show 1.2 million people who are their primary care-givers to older people living at home. As a rule, family care-giving of this group is a full-time job with 64% of those primary carers available round the clock, 26% several hours daily and 10% several hours a week. On average, this group cares for 36.6 hours a week.

Since the introduction of the long-term care insurance there has been a slight increase in the number of informal carers involved in support and care at home. 36% of all persons in need of care are cared for by one main care-giver, 29% are cared by 2 persons and 27% are cared by 3 and more persons. On average 2 persons, including the main family care-giver, are involved in domestic care arrangements.

If UK estimates of the carer population are applied to Germany ('one in eight people have a caring role') it would suggest that around 8 million 'low-level' (less than 20 hours per week) unpaid carers are not yet statistically recognised and no reliable information on this group appears to be available. Even the comprehensive EUROFAMCARE national background report on Germany only refers to an estimate "that roughly one third of all employed adults support or administer family care-giving" (Reichert, Naegelé, 1997, 1999).

Germany's *Soziale Pflegeversicherung* (long-term care insurance – LTCI)

Virtually all formal carer support in Germany developed from the implementation of the *Soziale Pflegeversicherung*, comparable to the UK situation where the *National Health Service and Community Care Act 1990* first formalised carer recognition and prompted subsequent development of policy, legislation and practical support.

Introduced on 1 January 1995, LTCI brought comprehensive improvements to the social security of people in need of continuing care. It is a fifth element of Germany's social security system, adding to health, accident, unemployment and retirement insurance.

LTCI predominantly provides benefits for domiciliary care, in an effort to enable beneficiaries to remain in their home and their family context for as long as possible.

LTCI is not designed to provide full financial cover, but to secure basic provision and thus ensure that, in the vast majority of cases, those affected no longer depend on income support to meet their care needs. To ensure adequate care, LTCI benefits can be supplemented by additional assistance on a means-tested basis, covering all nursing care needed in home or residential settings.

The benefits provided under LTCI vary with the level of care needed. Persons requiring care are assigned to one of three care levels. LTCI provides benefits for domiciliary and residential care (and for arrangements comprising both, eg regular respite care). Benefits granted under the long-term care insurance do not depend on the income or assets of the insured person.

Domiciliary care benefits

Practical services vary according to the degree of care needs. Instead of taking up benefits in the form of services, people with support needs can opt to receive cash payments if their care needs are met by relatives. This form of 'direct payment' serves as a personal continuing care budget. The uses to which it is put are not regulated and the person using it does not need not prove whether and how (s)he spent it. The only checks are to ascertain that the provision of care is ensured at all. Cash payments and benefits in kind can also be combined on a pro rata basis.

Benefits for unpaid carers

Particular importance is placed on improving the pension provision of unpaid carers who care for relatives for at least 14 hours a week in the latter's home and who, due to their caring responsibilities, do not work at all, or at least not more than 30 hours a week. LTCI insurance funds pay these carers contributions towards their statutory pensions which varying according to care level and extent of care provided, with amounts up to approx £250 per month.

Moreover, unpaid caring is covered under the statutory accident insurance. For the purposes of pension and statutory accident insurance, unpaid caring is placed largely on a par with forms of employment that are subject to social insurance contributions.

Some additional benefits envisaged to support care at home include:

- Nursing aids and subsidies to adapt homes to meet care needs
- Free care and nursing courses to train relatives, unpaid carers and volunteers
- A right to an additional care allowance for dependants requiring a considerable amount of supervision and care (eg dementia patients)

Support for residential care

In residential care, LTCI pays for care-related expenses, the costs for social care and for medical care according to the care level. The costs for accommodation and food are met by the persons in need of care themselves. Financing the investment costs of care facilities is a responsibility devolved to the individual Laender. Where the Laender cannot bear these costs in full, people in need of long-term care are billed for them separately.

How Germany's long-term care insurance is funded

LTCI is financed through 'progressive taxation' - contributions on a pay-as-you-go basis. Contribution rates are 1.7% of the gross income, with employers and employees usually contributing 50% each. More recently, pensioners have been included in mandatory contributions to address spiralling needs and funding deficits.

The introduction of LTCI was accompanied by the abolition of a national holiday in Germany to increase productivity and compensate employers for the additional cost of contributions. Contribution rates and the criteria for assessing long-term care needs can only be changed by federal legislation, while the amounts paid out as benefits can be varied locally.

In 2003, LTCI spent approx. 17.6 bn euros on about 1.89 m people in need of long-term care (1.28 m in domicilliary settings and 0.61 m in residential care home settings). Until then LTCI had shown a sound financial cushion built up in the early years which was able to absorb the deficits of recent years. Calling for different contribution rates for insured with children as opposed to those without children, a ruling of the Federal Constitutional Court will, when implemented, bring

the long-term care insurance added revenue, starting 2005, that will stabilise the financial situation also in the next few years.

Care service infrastructure

The introduction of LTCI has led to an increase of the service infrastructure. Between 1996 and 2004, services in the home and respite care sector have increased by approx. 20% to over 12,200, and in the residential sector by around 15% to over 9,200 long-term care facilities. The current care capacity in Germany is now considered sufficient so that unrestricted access to long-term care can be guaranteed for all.

Enhancing the quality of care

Care providers have a duty to ensure that service users are provided with care, nursing and attention in line with the generally recognised standards of medicine and nursing, and that services guarantee humane, dignified and stimulating care. This requires efficient and targeted cooperation of the Federal, Laender and local authorities and third-party providers. The Federal Government has led a range of initiatives for the development of additional care and quality standards.

Federal legislation has been amended to ensure uniform training and improve the professional image of geriatric nursing. This was supplemented by new professional requirements spelt out in the *Act to Reform Nursing Professions*. The aim has been to extend professional nursing care beyond hospital settings to be provided across home care, respite and residential sectors, to cover the diverse caring and life situations of families and their social environment.

The Government has also initiated several pieces of federal legislation to further develop the quality of the nursing care provided by licensing residential and care home services since January 2002.

Services for carers

The EUROFAMCARE National Background Report for Germany provides a useful graphic summary of services available to family carers and their key provider sectors (p48).

Services for family carers	Availability			Statutory	Public, Non-statutory	Voluntary		Private
	Not	Partially	Totally			Public funding	No public funds	
Needs assessment (formal – standardised assessment of the caring situation)			X	X4				
Counselling and Advice (e.g. in filling in forms)		X		X5				
Self-help support groups		X		X6		X		X
“Granny-sitting”		X		X7		X		X
Practical training in caring, protecting their own physical and mental health, relaxation etc.		X		X8	X9			
Weekend breaks		X		X10		X11		
Respite care services		X		X12				
Monetary transfers		X		X13				
Management of crises				X14		X15		
Integrated planning of care for elderly and families (in hospital or at home)				X16				
Special services for family carers of different ethnic groups		X			X17	X		

4 Laid down in the long-term care insurance law and conducted by the Medical Advisory Board assessing the level of dependency

5 The long-term care insurance companies are bound to counselling and advice (§ 7 SGB XI)

6 can be funded by the health insurance § 20, 3a, SGB V

7 Long-term care insurance promotes model projects who educate people as “voluntary senior citizens companions” for older people suffering from dementia aimed to relieve family carers. This could be named “granny-sitting” in a broader sense.

8 Long-term care insurance companies are obliged to offer courses for family carers and volunteers (§ 45)

9 Courses are also offered by professional nursing services and charitable organisations and are free

10 Day care is sometimes offered also on week-ends but is scarcely developed and less available

11 Partly offered by some non-profit organisations or private charitable societies like “Hamburgische Bridge”

12 Benefit of the long-term care insurance but with great differences in availability between rural and urban areas

13 Only benefits in cash through the long-term care insurance which can be seen as cash-allowance for family carers

14 In the course of ‘benefits for medical rehabilitation’ to prevent, remove or to lessen handicaps or chronic illness (§ 26, SGB IX)

15 also offered by self-help groups or charitable societies

16 In the state of planning: Introduced in the course of the “Health Modernization Legislation” in 2004: §104 a-h ‘integrated care’ to reduce intersectional problems in the continuity of care provision. See also the different model projects described in ProNetz

17 Regional model projects

In summary, the direction of UK/Scotland and German service provision for carers appear similar in many areas. This includes statutory rights to assessments, respite provision and support groups, crisis services, 'Joint Future' and hospital discharge procedures, and some transfer of funds to carers in the form of 'direct payments'.

Unlike the UK/Scotland, the provision of **counselling and emotional support**, and of **practical training**, are statutory duties in Germany, delegated or commissioned to regional and local providers, though it is noticeable that local provision still remains fragmented. Similar to Scotland and the UK, innovation and best practice increasingly exist but are fragmented and vary greatly between regions and local authorities.

Voluntary organisations representing the interests of carers advocate better service provision including the development of a nation-wide network of advisory and support centres for carers (similar to the PRTC's network of Carer Centres in the UK) and better respite provision.

Main outcomes of Germany's LTCI

Germany's LTCI has contributed significantly to give 'care' a higher political and economic profile and has met a national social policy objective in moving many dependent people out of their care needs-based dependence on social assistance. This has also provided relief on local authority care budgets.

In 2003, nearly 2 million people in Germany were in receipt of support through their social care insurance – more than originally anticipated would qualify by 2010. Of these, one third were in residential care and two thirds living at home. Contrary to 1994 expectations, home-based care in 2004 was still overwhelmingly provided by unpaid carers rather than local care services.

Through LTCI, unpaid carers receive financial support and pension credits. The ability to combine financial support with practical services, and to fund or access short-term respite care, prevents many unpaid carers from reaching crisis point. Unpaid carers are further supported by advice services and training courses in care.

Unpaid carers caring for people with dementia or mental health illness can access further services or funds in addition to LTCI. Since January 2002, the *Act Supplementing Domiciliary Care Services* created additional means of support for unpaid carers and enhanced the emotional and counselling support for carers. It also developed service structures and concepts, especially for dementia patients.

Economically, the introduction of LTCI has contributed to the development of local care infrastructures, particularly for home-based care services but also in residential care. Between 1996 and 2004 the number of home based care services has increased by 20% to over 12,200 services, and the number of residential services increased by 15% to over 9,200 services across Germany. This has increased choice for people with support needs and created approximately 200,000 new jobs in the care sector.

Key challenges

Ten years on following the introduction of LTCI in 1995, Germany's most acute problem has been a deficit of 700 million euro in 2003 (in 2001 LTCI income and expenditure still balanced) which is blamed on 'creative political accounting' in the light of Germany's difficult economic situation. The government has addressed this partially by bringing pensioners into the group of contributors. At the same time, insufficient increases in payments and services are being blamed

for gradually constraining the effectiveness of care provision. Although LTCI was never designed to provide complete cover of care needs, social care partners are concerned that basic provisions are being eroded.

Specific problems for the application of LTCI for dementia sufferers have also been raised, as their general care needs are extensive and still not sufficiently covered by the specific criteria applied to LTCI applicants. Tens of thousands of dementia sufferers are apparently still not in receipt of LTCI as a result.

More generally, the number of people with support needs and their carers who do NOT access LTCI is estimated to be very high, and their support needs are still inadequately researched and covered. The needs of care groups other than older people also appear under-researched and insufficiently supported.

References and links

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Germany's Long-Term Care Insurance: Putting a Social Insurance Model into Practice. Max Geraedts, Geoffrey V Heller and Charlene A Harrington, Heinrich Heine Universitaet Duesseldorf, Germany & University of California, San Francisco, USA. The Milbank Quarterly, Vol. 78, No. 3, 2000, Blackwell Publishers.

10 Jahre soziale Pflegeversicherung – Bilanz und Perspektiven. Statement von Dr Doris Pfeiffer, Vorstandsvorsitzende des VdAK/AEK, Mai 2004, Berlin.

Destatis – Statistisches Bundesamt – www.bfs.admin.ch/bfs/portal/de/index.html: Sozialhilfe in Deutschland 2003 – Entwicklung, Umfang, Strukturen. (Destatis – Federal Ministry for Statistical Information). Wiesbaden 2003

Bundesministerium fuer Gesundheit und Soziale Sicherung – www.bmgs.bund.de (Federal Ministry of Health and Social Security)

Appendix 3:

Voices of carers 1 – Report of a national survey of unpaid carers in Scotland

1. Methodology

1.1 Methodology of the survey

As part of this study, OPM initially designed and piloted a web-based survey of carers. The questionnaire was piloted from December 2004 until February 2005. The survey link was widely publicised through a range of media and networks and carers were invited to respond.

In March 2005, the web-based survey was revised. Further to this, and in order to widen access to the survey, a postal questionnaire was printed and distributed to over 25,000 carers with a cover letter and stamped addressed return envelope.

The surveys were distributed with the assistance of over 50 voluntary sector and care organisations including six national organisations (covering mental health, learning disabilities, profound physical disabilities, Crossroads respite schemes and patient carers) and the rest at a regional and local level. Carers in every local and health authority were accessed, as were carers from all caring situations, from addiction to the frail and elderly.

The survey ended on 31 May 2005 and 4267 completed questionnaires were returned (3575 postal questionnaires and 692 web-based questionnaires). The completed questionnaires were sent to the market research agency Plus Four, for coding and analysis.

1.2 Methodological issues

- In the tables of survey results in this document, * denotes a value of above 0 but below 0.5 per cent. Where figures do not sum to 100, this is due to multiple responses or computer rounding.
- Owing to an extremely small number of responses from people of differing ethnic origin or sexual orientation, comparison between these subgroups proved meaningless and therefore has not been reported.
- Overall, the sample is weighted towards those carers who are in contact with voluntary sector and care organisations and is not a random sample of all carers.

1.3 Presentation of data

This report provides an account of the responses to the survey.

Throughout the report, for each survey question, main findings are reported first for the whole sample and then for subgroups of the sample. Subgroup findings are not given where results are not significantly different from the results overall.

2. Profile of carers in the survey

2.1 Carers in the Care 21 Survey

Table 3.1 overleaf displays a breakdown of the sample profile. Of the 4267 carers and former carers that responded to this survey, the vast majority are adults that are currently caring (83%), just over a tenth (12%) of respondents are *former* carers over the age of 18 and further 3% are currently carers *under* the age of 18.

There are significantly more women in the sample compared to men (74% women vs. 24% men). Over three-quarters (78%) of respondents are aged 45 or over – a third (34%) aged between 45-59 years of age, over a fifth (22%) aged between 60-69 years and the same number again (22%) aged 70 years and over. Thirteen per cent of respondents are aged between 35 and 44, 3% are aged between 25 and 34, 1% are aged between 18 and 24, and the remaining 3% are under the age of 18.

Unfortunately, the sample is not as ethnically diverse as we would have hoped, with 97% of respondents describing their ethnicity as white, of which the majority (83%) classify themselves as white *Scottish*. Only a tiny minority of respondents described themselves as either mixed heritage, Asian, black or other ethnic group. However, it should be noted that this proportion is only marginally lower than the overall Black and Minority Ethnic (BME) population rates in Scotland. Other elements of the Care 21 project have been undertaken specifically to explore the aspirations and needs of both BME groups and young carers, the results of which are available separately.

The vast majority (76%) of those surveyed described their sexual identity/orientation as heterosexual. Only 1% describe themselves as either lesbian, gay or bi-sexual. A quarter (24%) of respondents chose not to answer (24%) this question.

The vast majority (72%) of the sample are not in paid employment – with 41% being retired, a quarter (24%) are of working age but not seeking work, 3% are unemployed but seeking work, 3% are students and 1% do voluntary work. Of those respondents who are in some kind of paid employment (28%) – 12% work full time, 13% work part time, and 3% are self-employed.

Responses were received from all 32 local authority areas in Scotland, although some areas are better represented than others. Larger numbers of completed questionnaires were received from areas such as Glasgow (12%), Fife (11%), Moray (9%), Edinburgh (6%), West Lothian (6%) and the Scottish Borders (5%).

Table 2.1 Sample profile

	Number of respondents N	Sample profile %
All respondents	4267	100
Paper	3575	84
Online	692	16
Type of carer		
Carer aged 18 or over	3561	83
Former carer aged 18 or over	516	12
Carer under 18	117	3
Former carer under 18	21	*
Not stated	52	2
Gender		
Male	1005	24
Female	3172	74
Not stated	90	2
Age		
Under 18	138	3
18-24 years	26	1
25-34 years	144	3
35-44 years	571	13
45-59 years	1448	34
60-69 years	951	22
70+ years	952	22
Not stated	37	1
Ethnicity		
White	4122	97
Scottish	3546	83
English	474	11
Irish	30	1
Welsh	13	*
Other White origin	59	1
Mixed	9	*
White and Black Caribbean	1	*
White and Black African	1	*
White and Asian	3	*
Any other mixed background	4	*
Asian or Asian British	20	*
Indian	5	*
Pakistani	12	*
Bangladeshi	1	*
Any other Asian background	2	*

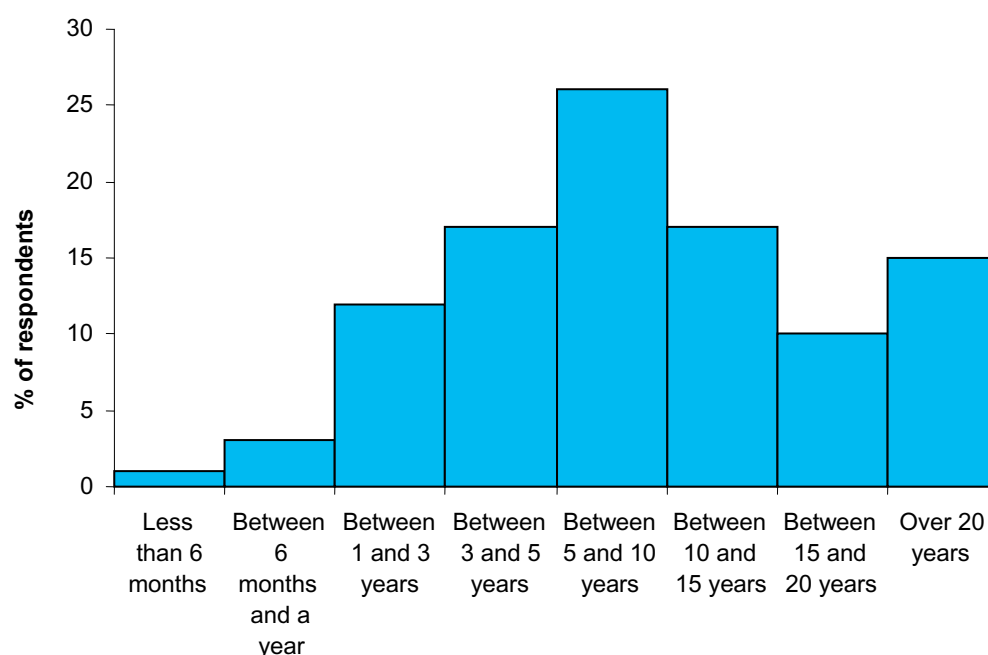
	Number of respondents N	Sample profile %
Black or Black British	2	*
Caribbean	0	-
African	1	*
Any other black background	1	*
Chinese	0	-
Other ethnic group	3	*
Not stated	111	3
Sexuality		
Heterosexual	3014	71
Lesbian	8	*
Gay	8	*
Bi-sexual	24	1
Other	199	5
Not stated	1014	24
Employment		
Full time paid work (30+ hours per week)	506	12
Part-time paid work (8-29 hours per week)	475	11
Part-time paid work (under 8 hours per week)	77	2
Retired	1733	41
Student	142	3
Self-employed	122	3
Unemployed (seeking work)	110	3
Not in paid employment (not seeking work)	1007	24
Voluntary work	22	1
Other	24	1
Not stated	49	1
Council Area		
Aberdeen City	108	3
Aberdeenshire	120	3
Angus	78	2
Argyll and Bute	97	2
Scottish Borders	213	5
Clackmannanshire	20	*
West Dunbartonshire	92	2
Dumfries and Galloway	66	2
Dundee City	23	1
East Ayrshire	47	1
East Dunbartonshire	25	1
East Lothian	151	4
East Renfrewshire	20	*
Edinburgh, City of	244	6

	Number of respondents N	Sample profile %
Falkirk	183	4
Fife	461	11
Glasgow City	530	12
Highland	183	4
Inverclyde	19	*
Midlothian	79	2
Moray	375	9
North Ayrshire	18	*
North Lanarkshire	88	2
Orkney Islands	75	2
Perth and Kinross	157	4
Renfrewshire	24	1
Shetland Islands	3	*
South Ayrshire	46	1
South Lanarkshire	100	2
Stirling	28	1
West Lothian	246	6
Eilean Siar	3	*
Invalid/not stated	345	8

2.2 Duration of caring

Most of those carers surveyed have been caring for a substantial length of time, with over two-thirds (68%) of respondents having been a carer for over 5 years: 26% have been caring for between 5 to 10 years, 17% for between 10 to 15 years, 10% for between 15 to 20 years and a massive 17% for over 20 years.

Fig. 2.1 Duration of caring



Base: 4193

Non-response: 74

Those people surveyed who care for people with learning disabilities or mental health problems tend to have been caring for over 20 years; 38% of those caring for people with learning disabilities, and 19% of those caring for people with mental health problems fall into this category.

Women are slightly more likely to have been caring for longer than men – 26% of women have been caring for over 15 years, compared to 18% of men.

Those people working full-time are less likely to have cared for over 15 years (18% of full-time workers), compared to those who are retired (27%) or unemployed (25%).

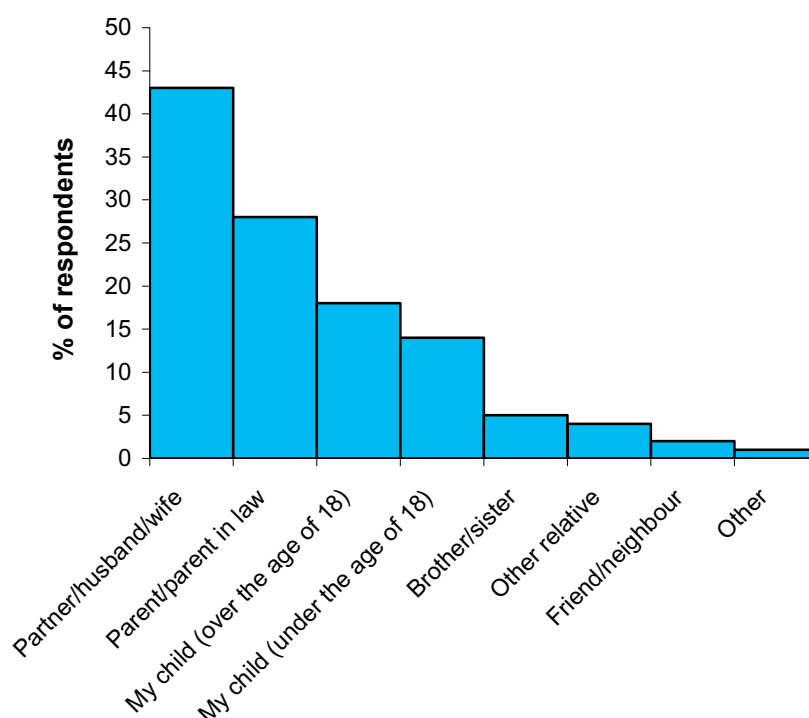
2.3 Relationship to the person(s) cared for

Respondents were asked to specify their relationship with the person(s) they care(d) for. A number of categories were provided and respondents were asked to tick all that applied, given that a number of those surveyed care for more than one person.

As might be expected, the vast majority of those surveyed care for a close family member; over two-fifths (43%) of respondents care for their partner or spouse, accounting for the largest proportion of those surveyed. Over a quarter (28%) care for a parent, or parent-in-law.

A substantial number of carers are looking after their own children – 18% care for their adult child, and 12% care for their own child (under the age of 18). A smaller proportion of respondents care for a brother or sister (5%), a relative other than those specified (4%), or a friend or neighbour (2%).

Fig. 2.2 Relationship to the person(s) cared for



Base: 4183

Non-response: 84

Men are significantly more likely than women to care for their partner, husband or wife – two-thirds of men (65%), compared to just over a third of women (35%). Women on the other hand are significantly more likely than men to care for their child – 21% care for their own child over the age of 18, and 17% for their child under the age of 18; the figures for men are 9% and 5% respectively. Women are also more likely than men to care for a parent or parent-in-law: 30% of women, compared to 20% of men.

In terms of age, the findings fit in broadly with expected trends. Those surveyed under the age of 18 are most likely to care for either a sibling (47%), or a parent (51%), a trend that is also seen in the 18-24 year-old age group. As the respondents get older (between 25 and 44 years of age), they are more likely to look after their own child under the age of 18 – over half of this group care for their child. Between 45 and 59 years of age, increasing numbers of respondents begin caring for parents and parents-in-law (42%), while a quarter of this age group (25%) care for their own child (aged over 18). Finally, in terms of the older

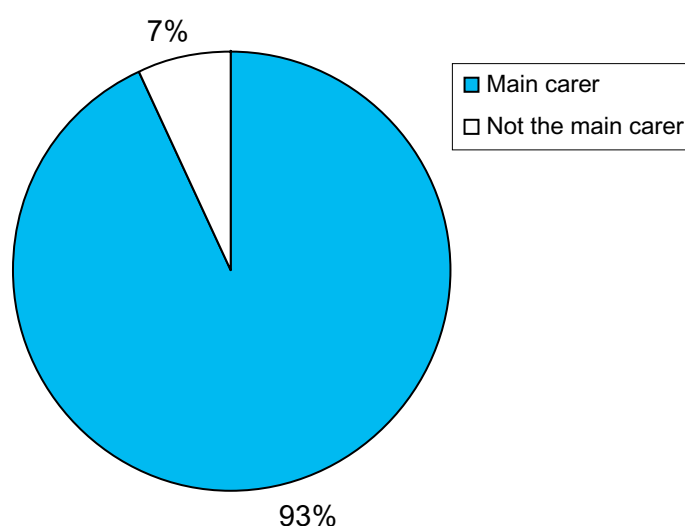
age groups (60-69 years of age and 70+), those surveyed tend to care for their spouse – 76% of carers over the age of 70 look after their partner.

Heavily intensive carers (those who care for over 50 hours a week) are far more likely to care for their partner than those who have less intensive care roles; half care for their partner/husband or wife, compared to just 14% of those who care for less than 10 hours a week. This group are also significantly more likely to care for their child; one in six (17%) care for their child under the age of 18. Carers with less intensive roles (less than 10 hours a week) are much more likely to care for their parent or parent-in-law (43%).

2.4 Caring commitment

As figure 3.3 shows, the vast majority of the sample (93%) said that they are the main carer, and are therefore responsible for the overall majority of caring duties.

Fig. 2.3 Responsible for caring commitment



Base: 3311

Non-response: 956

Carers under the age of 18 are least likely to be the main carer. Of all carers under the age of 18, 61% are not the main carer – a significantly higher amount than those carers who are over the age of 18. Similarly, respondents over the age of 70 are far more likely to be the main carer, perhaps in light of the fact that they may be caring for an elderly husband or wife.

In terms of work status, as one would expect, those working full or part-time are far less likely to be the main carer than those who are unemployed or retired. This may be indicative of the high levels of responsibility that carers often take on; making balancing paid work and caring extremely difficult.

2.5 Reasons why the person being cared for needs care

Respondents were asked what best describes the reason they have become carers. Although carers could select more than one condition/illness of the caree, the answers should refer only to the person they spend the most time caring for.

As table 3.2 below shows, there are a wide variety of reasons why the persons cared for have to be looked after. Obtaining a greater understanding of this group of people will in turn help to understand further the needs of their carers.

The most common reasons are some form of physical disability or sensory impairment (44%) and/or a physical illness of some kind (44%). The category physical disability or sensory impairment covers a variety of conditions including partial or full sensory impairment and/or some form of physical disability. Physical illness covers a variety of both short and long-term illnesses, including cancer, arthritis, asthma and multiple sclerosis.

Over a quarter (26%) of those cared for fall under the category 'frail and/or elderly', a further 17% of those needing care are suffering from dementia or Alzheimer's.

Almost a quarter (24%) of people cared for suffer from some form of mental illness, a category that covers a variety of conditions – from brain injury and memory loss to severe depression.

A significant proportion of respondents care for people suffering from some form of learning disability (21%), (this covers a number of conditions including Downs Syndrome, Autism and Dyspraxia) and 14% care for a child with special needs.

Only 2% of those surveyed stated that the main reason for their caring responsibilities is the caree's addiction to substances such as drugs or alcohol.

Table 2.2 Reason(s) why the person being cared for needs caring

	%
Physical disability/sensory impairment	44
Physical illness	44
Frail/elderly	26
Mental illness	24
Learning disability	21
Dementia/Alzheimer's	17
Children with special needs	14
Addiction	2
Other	3

Base: 4187

Non-response: 80

Those suffering from a learning disability are far more likely to need long-term care, and intensive levels of care; 46% of people who have been caring for more than 15 years, and 27% of people caring for over 50 hours a week have cared for someone with a learning disability. The same seems to apply to those caring for children with special needs – 17% of respondents who have cared for over 15 years and 18% of those caring for over 50 hours a week. For these two conditions, both long-term and heavily intensive caring seem to go hand in hand.

While for most conditions, gender seems to have little or no statistical significance; it appears that men are more likely to care for those suffering with a physical illness (52% of men, compared to 41% of women). Women on the other hand, are far more likely to care for someone suffering from a learning disability (25% of women compared to 11% of men), or a child with special needs (17% of women compared to only 6% of men).

As is the case with the relationship between respondent and caree, in terms of age, the findings fit in broadly with expected trends. Respondents under the age of 18 are statistically more likely to care for someone suffering from addiction (6%), or with mental illness (34%), compared to other age groups, which would fit in broadly with the observation that they are most likely to care for a parent.

Those surveyed aged between 25 and 44 are most likely to care for those with learning disabilities or children with special needs; 45% care for those with a learning disability, while 53% of 25-34 year olds and 48% of 35-44 year olds care for children with special needs. Again, this relates to the observation above that, most of this age group tend to care for their own child.

Amongst the oldest three age groups (45-59, 60-69 and 70+ years of age), a large proportion tends to be responsible for caring for those with physical illnesses and/or Dementia/Alzheimer's. The findings suggest that as age increases, so does the likelihood that a person will care for someone with age related conditions such as a physical illness or dementia.

2.6 Intensity of caring

Respondents were asked to specify the average length of time that they spend looking after the main person they care for. As table 3.3 shows, the sample is dominated by carers with the heaviest caring commitments, with the vast majority (63%) spending over 50 hours per week undertaking caring responsibilities.

For those respondents who answered 'other' (2%), this tended to be because their caring responsibilities varied from week to week, dependent on the health of the person that was being cared for.

Table 2.3 Average length of time spent caring per week

	%
50+ hours	63
40-49 hours	8
30-39 hours	8
20-29 hours	7
10-19 hours	8
0-9 hours	5
Other	2

Base: 4133

Non-response: 134

While most of the trends have been noted above, in terms of the relationship between intensity of caring, and condition for example, a number of further observations can be made.

With respect to respondents under the age of 18, the intensity of their care experience seems to vary considerably. While 34% of this age group care for less than 10 hours a week, 21% care between 30 and 39 hours a week, and are significantly more likely to do this than other age groups. Given that many of those under 18 will still be attending school – this amount of caring is extremely high.

Older carers (70+) are far more likely to spend over 50 hours a week caring than those aged between 45 and 59 years of age (74% compared to 57% of each age group), and those in the 25-44 year age group are more likely to spend more time caring than those under the age of 24.

Heavily intensive carers are significantly much more likely to have been caring for a long period of time; almost three-quarters (71%) of carers who spend at least 50 hours a week caring, have been caring for over five years and 17% have been caring for over 20 years.

2.7 Caring responsibilities

Respondents were asked what kinds of things they usually do/did for the person that they care(d) for. A number of statements were provided and respondents were asked to tick all that they felt applied to them. In addition, they were given the opportunity to make additional comments in answer to this question.

As outlined in table 3.4, it is clear that most of the statements apply in some way to the majority of respondents – all nine of the statements given in the survey are applicable to the majority of respondents, illustrating the variety of duties that many carers have to undertake.

The task that the majority of respondents undertake for the person they care for is offering some form of practical help (88%), such as shopping, laundry, and helping with travel to appointments.

Large proportions of respondents also believe their main tasks include keeping the person they care for company (82%), going out with the person they care for such as taking them to see friends, or going for a walk together (77%); helping them with paperwork (77%) and offering emotional support (75%).

The sheer amount of responsibility taken on by a significant number of carers is evidenced by the fact that the majority of carers also said that they provide personal care (71%) and or nursing/medical care or therapy (70%) for the person they care for.

Table 2.4 Duties undertaken by carers

	%
Other practical help	88
Keeping company	82
Going out	77
Helping with paperwork	77
Emotional support	75
Personal care	71
Nursing/medical care or therapy	70
Physical help	60
Communications and speaking up for them	57
Full care	2
Financial help	*
Other	1

Base: 4201

Non-response: 66

Those respondents who have been caring for over 15 years are significantly more likely to undertake the majority of duties listed above, compared to those who have been caring for a shorter period of time. Indeed, the only duty that this cohort is less likely to undertake is the category of physical help. For almost all of the remaining categories, as the duration of caring increases, so does the amount of carers' responsibility. For example, 67% of carers who include 'personal care' as something that they regularly do with the person they look after, ranges from 58% of those carers who have been caring for less than a year, to 65% of those who have been caring between one and five years, to 73% of those caring between five and 15 years, to 76% of those who have been caring for longer than 15 years. This pattern is repeated for the majority of other categories, illustrating the variety of roles and responsibilities that carers have to undertake, particularly when caring for significantly long periods.

Importantly, the trend is the same with respect to *intensity* of caring. Those respondents who spend over 50 hours a week caring for the main person under their charge, are without

exception significantly more likely to undertake all of the responsibilities outlined above, than those who care for shorter periods of time. Again, as the intensity of caring increases, so too does the proportion of respondents that are likely to perform each of the duties. To use the example of personal care again, while only 18% of those caring for between 0 and 9 hours a week, over four times as many of those respondents who care for over 50 hours a week take on this role (82%). The pattern is repeated in all other categories – while one-fifth (20%) of those respondents who care for less than 10 hours a week provide the caree with some form of physical assistance (such as using the stairs and walking), over two-thirds (69%) of carers who spend over 50 hours a week take on this responsibility.

Those respondents who care for the frail/elderly are the most likely to assist with the largest variety of responsibilities. In particular, practical help (95% of respondents), helping with paperwork (92%) and keeping the caree company (90%) are the main responsibilities that this group undertakes.

Those people who care for someone with a learning disability or a child with special needs tend to undertake a mixture of emotional support and physical help. 82% of those respondents who care for someone with a learning difficulty and 81% of those who care for children with special needs provide emotional support, and a similar proportion of both groups (79% and 77% respectively) help with communication and speaking up for the caree.

Those carers surveyed who look after someone with mental health problems are significantly more likely to spend time going out with the person they care for (76%), and providing emotional support (81%) than undertaking more physical forms of care such as personal care (59%) or physical help (45%).

3. Carers' health and well-being

3.1 Impact of caring on a person's health

Respondents were asked to identify which of a range of given symptoms they had experienced as a result of being a carer. Participants could tick all that applied.

Overall, caring has had a negative impact on the health and well-being of the majority of carers. Only 5% feel that their health has not been affected in any of the ways listed.

In particular, most carers have experienced tiredness as a direct result of their caring responsibilities (84%). Almost three-quarters of respondents have reported general feelings of stress (72%) or sleep disturbance/insomnia (70%), and a further two-thirds have felt anxious (65%), short-tempered and irritable (62%) or depressed (61%).

Table 3.1 Impact of caring upon carers' health

	%
Feeling tired	84
General feeling of stress	74
Disturbed/lack of sleep	72
Feelings of anxiety	67
Short tempered/irritable	64
Feeling depressed	63
Physical strain	47
Loss of appetite	22
No, my health has not been affected in any of these ways	5

Base: 4118

Non-response: 149

In terms of intensity of caring, it is important to note that those respondents who care for more than 50 hours a week are far more likely to experience all of these conditions, compared to those who care for shorter amounts of time. Indeed, the health of those people who care for between 0 and 9 hours a week is far less likely to be affected by their responsibilities – 15% of this group report that their health has not been affected in any of these ways, compared to 4% of those who care for more than 50 hours per week. Without exception, the findings show that for each of the symptoms given above, the longer a person spends caring per week, the higher the proportion of people that are affected by each, illustrating that the more intense the caring experience, the greater the impact on their health.

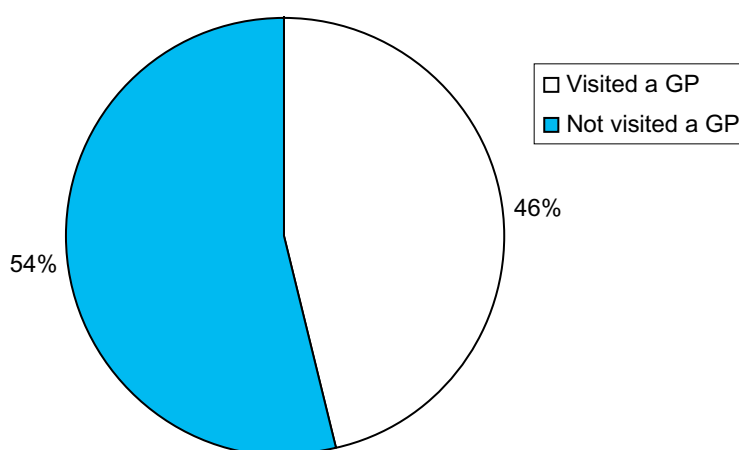
It appears that carers who are responsible for looking after children with special needs and people with learning difficulties are much more likely to suffer from *all* of the symptoms above than those who care for the frail/elderly or someone with a physical illness. For example, 87% of people who look after children with special needs report experiencing a general feeling of stress, compared to 74% of those responsible for looking after the frail/elderly. This implies that the type of condition of the caree is likely to have a direct impact upon the health and well-being of the carer.

Without exception, women are significantly more likely to experience all of the above conditions than men: for example, 87% of women report having felt tired, compared to 76% of men; 66% of women report having felt depressed, compared to 5% of men and over three-quarters of women (77%) report having a general feeling of stress compared to less than two-thirds of men (64%).

Further to this, respondents were asked if they have visited their GP within the last 12 months as a result of their health being affected through their caring responsibilities.

As figure 4.1 shows, almost half (46%) of the respondents have visited their doctor within the last 12 months because their health has been affected by being a carer. This is a high proportion and illustrates the severity of the effect that caring may have upon the health and well-being of the carer.

Fig. 3.1 Proportion of respondents who have visited a GP within the last 12 months as a result of their caring responsibilities



Base: 4046

Non-response: 221

Those carers who reported that caring has had some sort of impact upon their health and well-being, as outlined in table 4.1 were also far more likely to have visited a GP within the last year, as a result of their caring responsibilities.

Respondents were also asked to describe any other ways in which caring has affected their health. A significant proportion carers report that they are also suffering from an illness of

their own. More than one in twenty carers (6%) stated that they are suffering from a disability or chronic illness, whilst others report that they have mental health issues (3%); on-going general health problems (3%) or suffer from stress and stress related illnesses (2%).

3.2 Impact of caring on a person's social life

Respondents were asked if their own personal/social life had been affected as a result of being a carer. They were provided with seven statements and asked to tick all that they felt applied to them.

A large proportion of respondents (89%) stated that caring has had an effect upon their personal life, and to a lesser degree, upon their education and career. Over three-quarters (78%) of those surveyed felt that caring limited their free time, while 64% of respondents felt that it impacted upon their family life.

Just under half (46%) of respondents reported feeling lonely and/or isolated as a result of their caring, and almost a third (31%) have experienced financial problems. A similar proportion of those surveyed reported that caring has impacted negatively upon their career (28%), while significantly less (7%) stated that it had a negative effect upon their education.

Table 3.2 Impact of caring upon respondent's social life

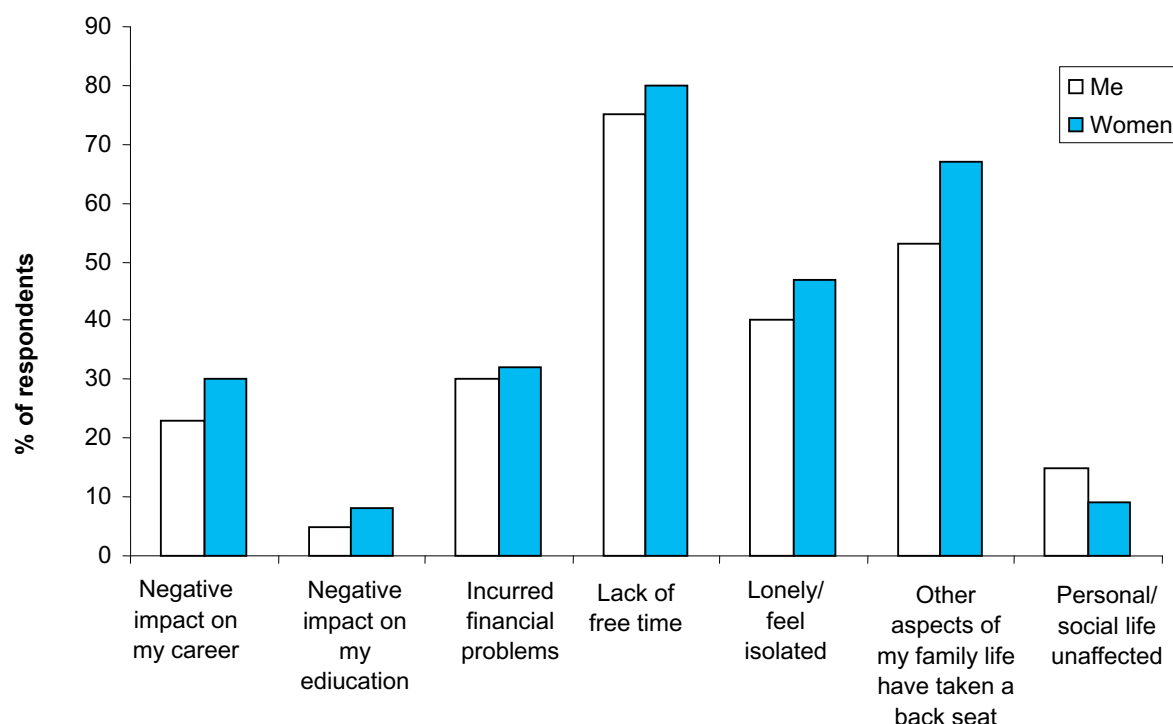
	%
Lack of free time	78
Other aspects of my family life have taken a back seat	64
Lonely/feel isolated	46
Incurred financial problems	31
Negative impact on my career	28
Negative impact on my education	7
No, my personal/social life has not been affected	11

Base: 4069

Non-response: 198

As shown in figure 4.2, for all of the statements above (excluding the incurrence of financial problems), women are *significantly* more likely than men are to experience a negative impact upon their social life as a result of their role as carer. Furthermore, 15% of men reported no change in their personal/social life, compared to only 9% of women.

Fig. 3.2 Impact of caring upon a person's social life, by gender



Base: 4069

Non-response: 198

Those respondents who are working either full or part-time, or are unemployed were significantly more likely to have experienced some sort of impact upon their social/personal life, compared to those who are retired.

Overall, the age groups whose personal and social lives appear to be the most affected are those between the ages of 25 and 69 years of age; in other words, those that are neither at the start nor the end of their caring career. In light of previous observations that those under the age of 18 are least likely to be the main carer, and likely to spend the lowest amount of time caring per week, it follows that their social life is less likely to be affected than someone who is caring for over 50 hours a week. Similarly, at the other end of the spectrum, those respondents over the age of 70, while being most likely to be the main carer, are also most likely to be caring for their spouse, and hence may not find that their social life or career have been negatively affected.

Negative impact on career

Part-time workers seem to have experienced the heaviest impact upon their career with almost half (47%) having been affected, compared to 39% of full-time workers and just 11% of retirees. Part-time workers may be most affected by their caring duties as a result of having to work a reduced number of hours per week in order to fulfil their caring roles.

Negative impact on education

Unemployed respondents are the most likely group to have had their education affected by caring. Thirteen per cent of people surveyed, who describe themselves as unemployed, believe that caring has had a negative impact on their education.

Carers under the age of 18 (19%), and those aged 18-24 years old (28%) are also the most likely to report a negative effect upon their education.

Feeling lonely or isolated

Unemployed respondents are the most likely to feel lonely or isolated as a result of their caring responsibilities; 58% of unemployed respondents report experiencing some sort of loneliness, compared to 42% for both full and part-time workers, and 39% of retired people surveyed.

Incurred financial problems

Unemployed respondents were the most likely to say that they had incurred financial problems (49% of unemployed carers compared to 17% of retired carers).

Personal or social life is not affected

In terms of age, the groups most likely to report that their personal life has not been affected are those under the age of 18 (49%) and those over the age of 70 (17%).

Carers were also asked if their social life had been affected in any ways other than those listed. The largest proportion of respondents (12%) stated that caring had affected relationships with friends and family.

A substantial proportion of carers surveyed raised the issue of socialising. One in fourteen respondents (7%) reported that their social life had become non-existent as a result of being a carer, while many others stated that caring had placed restrictions on their socialising (5%), or had given them with reasons for not socialising (a further 5%).

Those carers surveyed that care for over 50 hours a week are significantly more likely to assert that their social life is non-existent (8%), and that caring has affected relationships with friends and members of their family (14%). Those respondents with heavy care responsibilities were also significantly more likely to report that caring had given them reasons to stop socialising (6%), and that it had affected their personal interests and well-being (6%). Those who care for an average of between 30 and 49 hours per week, are also significantly more likely to report a non-existent social life (8%) and changes in their relationships with family and friends (12%), suggesting that the more care intensive the role, the greater the likelihood of it affecting the carer's social life.

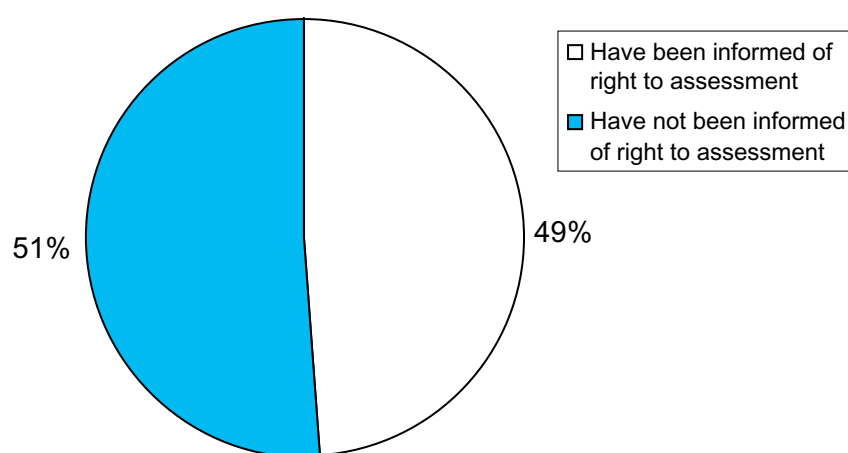
Other ways in which the personal lives of respondents have been affected included disruption to holiday plan (3%), the personal interests and well-being of the carer being affected (5%), and a negative impact on the respondent's career (2%).

4. Local support services for carers

4.1 Carer assessments

Respondents were asked if they had ever been informed of their right to an assessment of their needs as a carer. As figure 5.1 illustrates, over half of respondents have not been informed of their right to a carer assessment (51%).

Fig. 4.1 Carer assessments



Base: 3641

Non-response: 626

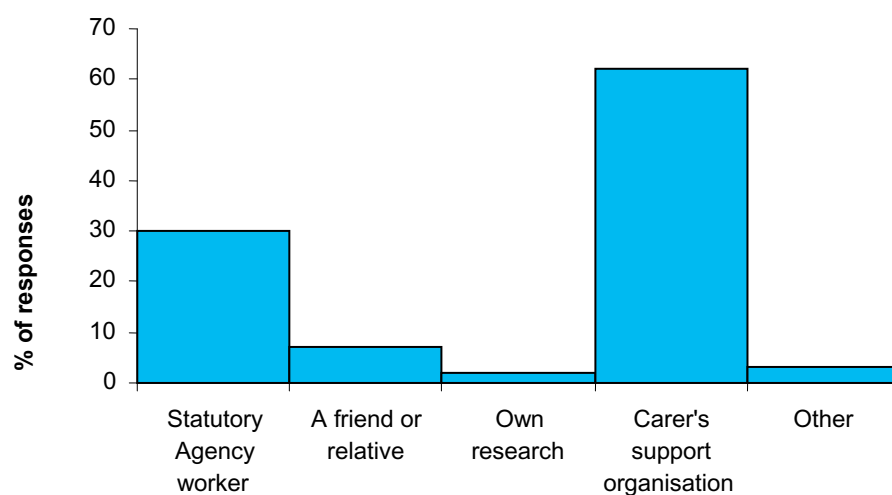
The findings suggest that carers above the age of 60 are significantly more likely to be informed of their right to a carer assessment than younger respondents. 53% of 60-69 year olds and 55% of carers over the age of 70 have been informed of their right to an assessment, compared to only 38% of 25-34 year olds.

When the results are examined in terms of the average weekly length of time spent caring, and the length of time that the respondent has been a carer, there is very little difference reported. People who have been caring for a long time, and/or those with very time intensive care responsibilities, are no more likely to have been informed of their right to assessment than those who have been caring for a much shorter period of time, and with a less intensive role.

We asked respondents who had been informed of their right to an assessment of their needs as a carer who had informed them about this first. It is interesting to observe that support groups are the most likely source of information with respect to carer assessments; almost two-thirds (62%) of those surveyed first heard of the assessment through their support group.

Almost a third (30%) of those carers surveyed heard from a statutory worker, and 7% heard from a friend or relative.

Fig 4.2 Who informed of the carer assessment first



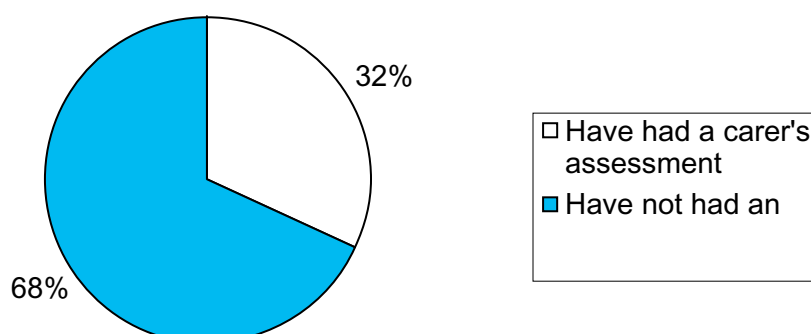
Base: 1764

Non-response: 33

While there is little variation between the different subgroups, and where they are most likely to have obtained information from, it seems that those carers who are in full or part-time employment are the most likely to have conducted their own research into carer assessments; 4% conducted their own research, compared to 1% of retired and unemployed people.

Respondents were then asked whether they have actually had a carer assessment. Only a third (32%) of those surveyed have had a carer assessment.

Fig 4.3 Proportion of respondents who have had a carer assessment



Base: 3546

Non-response: 721

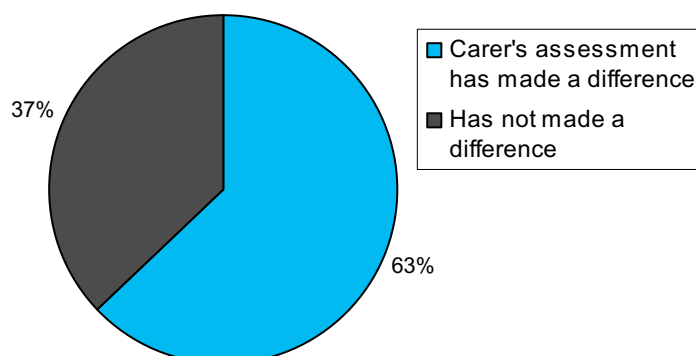
Again those surveyed over the age of 70 are the most likely to have had a carer assessment with 39% of this age group having had an assessment, compared to just 22% of the 25-34 year olds surveyed.

In terms of the condition of the carer, the least likely category to receive a carer assessment are those suffering from addiction – only 20% of this category have received a carer assessment, compared to 35% of the frail and elderly.

The work status of respondents also seems indicative of the likelihood of a carer assessment occurring – those carers surveyed who work full or part-time are significantly less likely to have had a carer assessment than those who are unemployed or retired. Only 23% of full-time workers, compared to 35% of retirees have had a carer assessment.

The fact that only 59% of those people who have been informed of their right to a carer assessment have actually received one is a cause for concern. Especially in light of the fact that of those people who have had an assessment, the majority (63%) said it had made a difference.

Fig 4.4 Effectiveness of the carer assessment



Base: 1075

Non-response: 44

Of those respondents who did not find their carer assessment helpful, the majority were from high intensity caring roles. Forty percent of people who care for more than 50 hours a week, did not find the assessment helpful, compared to 5% of people caring for less than 10 hours a week.

Those respondents caring for someone who is frail and elderly found the carer assessment the most helpful (72% of carers), as did those caring for someone who has physical disability/sensory impairment (61%). Those conditions where the carer assessment was less successful were for those who care for someone with a learning disability (55%) or a child with special needs (59%). This suggests that more consultation is needed to find out why the assessment is not meeting the needs of certain groups of people.

Retired people (72%) and those people who are working full-time (66%) were significantly more likely than others to report that the assessment has made a difference. Yet people working full time are the least likely to have had an assessment.

4.2 Carer breaks

Short breaks from caring are known to have positive benefits for the carers and the person they care for. The survey went on to ask respondents about their experience of carer breaks, and the suitability of the respite care that they have accessed. By gaining a better understanding of carer breaks, more can be done to ensure that the breaks offered are appropriate to the needs of both the carer and the person being cared for.

Initially, respondents were asked to detail what arrangements they used when they last had a break from providing care for over two days.

As table 5.1 details, it is evident that people have used a number of different options; the most common method of respite care used by respondents being a nursing or residential home, with over a fifth (21%) of carers surveyed having used this method most recently.

The role of friends and relatives appears to be very important in terms of providing help with breaks – 17% of carers surveyed stated that a friend or relative staying with the person cared for was the most recently used method of respite care, while a further 12% of carers reported that the person they care for had gone to stay with a friend or relative.

Smaller proportions of respondents used an arranged holiday (6%), an NHS hospital (4%) or support from external/paid carers (3%).

Nevertheless, a significant proportion of respondents, for a variety of reasons, have not had a short break from the person in their care (39%). One of the most common reasons for this is because they do not know how to access one, with 14% of carers surveyed stating that this is the reason why they have not had a break.

The same proportion of respondents again, said they had not had such a break because they have not required it (14%).

Table 4.1 Arrangements used on most recent break from caring

	%
Nursing or residential home	21
Friend or relative staying with person cared for	17
Stay with relatives or friends	12
Arranged holiday	6
NHS hospital	4
Support from external/paid carers	3
Local Authority hostel	2
Stay with a volunteer family	1
Person left on own	*
Breaks while at a day centre	*
School trip	*
Not had such a break because I do not know how to access one	14
Not had such a break because we have not required it	14
Never had a break (unspecified why)	5
Was offered such a break but it was not suitable to our needs	4
Do not want to leave the person cared for	2
Share this responsibility	*
Financially unable to take a break	*
Other	1

The age groups that are most likely not to know how to access a care break are those aged between 18 and 44 years of age. 24% of 25-34 year olds stated this as the reason why they have not had a recent break, compared to only 11% of those respondents aged 70 or older. This older cohort is far more likely to claim that they have not had a break because they do not require it; over a fifth of the over 70s noted this as their answer (21%), compared to 10% of the 25-34 age group.

Those respondents who felt that the care break offered to them was not suitable to their needs were asked to explain why. Over a quarter of respondents (26%) reported that the reason why the break was unsuitable was that the person cared for was unhappy, or would not agree to being left. A lack of suitability to the needs of those cared for was cited by over a tenth of respondents (11%) as the reason why the respite care was unsuitable.

Further to this, 7% reported that they wanted a holiday together with the person they care for, 5% stated that the care package offered was too expensive, and 3% noted that the lack of transport offered was the reason for not taking the break.

Respondents were asked what kind of care breaks would be most helpful to them and the person for whom they provide care. Respondents could select up to three of the 12 potential options provided, and as summarised in table 5.2 below.

In terms of the length of time of each of the breaks, the majority of respondents seemed to opt for regular breaks lasting for a few hours, as opposed to longer breaks lasting a few days, or a week or more. That said, as table 5.2 shows, the responses overall were very varied, with no one particular type of break receiving substantially more support than another, highlighting the very different needs of carers, and the extent to which different caring breaks need to be tailored to the needs of individuals.

A significant proportion of respondents state that they would like some sort of supported holiday for themselves and the person whom they care for, highlighting that for many of the carers surveyed, a joint break would be preferable to one where the caree is being looked after. Almost a third (31%) of carers surveyed would like regular short breaks with the person that they care for, and a similar proportion of respondents (30%) would like a supported break with their caree lasting at least a week.

Of those respondents who would prefer to have a care break where the person they look after is placed in a residential or care home, one in four people surveyed (25%) would like these breaks to be over a week long (25%), compared to just over one in 10 (11%) who would prefer the breaks to last a few days.

Many carers expressed a preference for visits from qualified care staff, (either in their own home or that of the caree). Of these respondents, a larger proportion (28%) expressed a preference for shorter, weekly care breaks, compared to regular breaks lasting a few days (19%).

Over one-fifth of respondents (22%) stated that they would like family and friends to help out weekly for a few hours, although significantly less (11%) would opt for a placement of a few days with a volunteer family, relatives or friends.

Less than one in 20 people surveyed expressed a preference for a rehabilitation or social care break (4%) lasting for a week or more.

Table 4.2 Suitability of potential care breaks for the carer and caree

	%
Regular weekly breaks lasting a few hours provided by:	
Care staff coming to your home, or the home of the person cared for	28
Day care at a local centre or in the community	24
Family members or friends	22
Qualified volunteers or staff in the evening or at weekends	22
Regular breaks lasting a few days, provided by:	
A short holiday break with the person cared for	31
Care staff coming to your home or the home of the person cared for	19
Residential/Care Home type accommodation	11
Placements with a volunteer family, relatives or friends	11
Regular breaks lasting at least a week provided by:	
Supported holidays with the person cared for	30
Residential/Care Home type accommodation	25
Support from friend or support from family members	18
Rehabilitation or hospital care	4
Other	4

Base: 3154

Non-response: 1113

Heavy intensity carers (those who care for over 50 hours a week) are the most likely to express a preference for residential/care home accommodation for the person they care for; 21% would like these breaks to be a few days long, while over a quarter stated (26%) that they would like them to be at least a week long. In comparison, low intensity carers (less than 10 hours a week) are the least likely group to express a preference for this type of care break (8% and 21% respectively).

Conversely, respondents with heavy intensity care responsibilities are least likely to report a preference for care breaks that are supported by family members or friends. One in five (20%) respondents state that they would prefer friends and family members to provide weekly care breaks of a few hours and 15% would like family/friends to support them during week-long breaks.

As with many other areas, those respondents who either care for a child with special needs or someone with learning difficulties have very similar needs, which tend to concentrate around a preference to keep the family together. Of those carers surveyed who look after a child with special needs, 36% expressed a preference for having qualified volunteers or staff helping in the evenings or weekend, as did a similar proportion (32%) of respondents caring for someone with learning difficulties. High proportions of both cohorts of carers also expressed a preference for joint short holiday breaks of a few days or more (37% for carers of children with special needs and 34% of those caring for someone with learning difficulties) or for a week or longer (39% and 37% respectively).

Those respondents that care for a frail or elderly person are significantly more likely to express a preference for short, frequent breaks. In particular, respondents were significantly more likely to express a preference for having care staff visiting their own home or that of the caree (34%) on a weekly basis for a few hours, or short, regular day care breaks at a local centre or in the community (28%). This group of respondents were much less likely to report that they preferred to go away with their caree – responses tended to focus around having qualified care staff come to their (or the caree's) home (24%) or in a local residential/care home (22%) for a few days.

Those carers looking after someone with mental health issues were significantly more likely to have a preference for supported joint holidays with the person that they care for; either for a few days (35%) or for at least a week (33%).

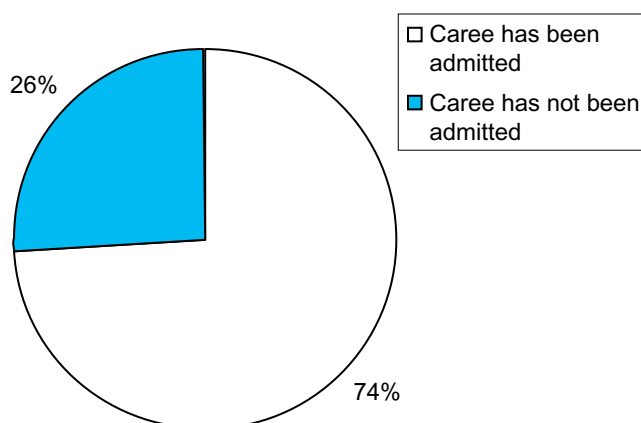
In terms of employment status, unemployed respondents are significantly more likely to express a preference for supported holidays with the person that they care for – 37% of respondents stated that they would like a short break of a few days with the caree, and a similar proportion (36%) stated that they would prefer a break of at least a week.

Those respondents that are in full or part-time work, tended to express a preference for help from qualified volunteers or staff. Almost one in three part-time workers (30%), and a similar proportion of full-time respondents (28%) would like such help in either in the evenings or weekends, and around one in four would like care staff coming to the home for a few days (22% of part-time and 28% of full-time workers surveyed).

4.3 Impact of extra support for carers on hospital admissions

Respondents were asked to detail whether or not the person they cared for had ever been admitted to hospital. Almost three-quarters of respondents (74%) stated that the person in their care had been admitted to hospital.

Fig. 4.5 Number of carers that care for someone who has been admitted to hospital

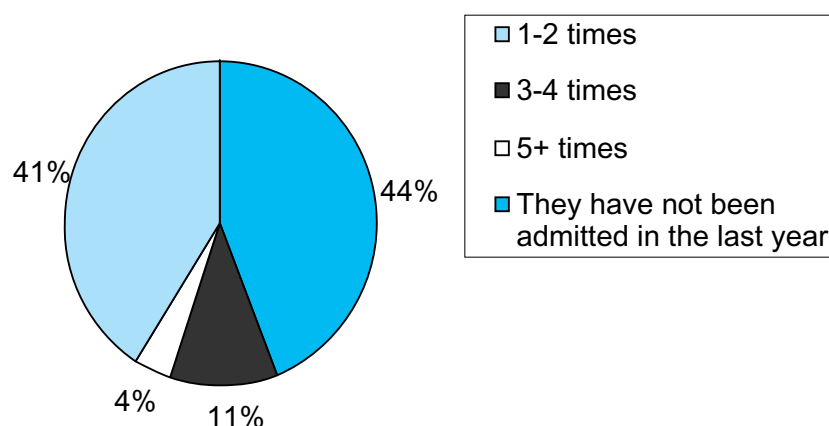


Base: 3803

Non-response: 464

Respondents who stated that the cared for person had experienced hospital admittance were asked to detail how often this had occurred. The majority of respondents (44%) care for someone who has been in hospital once or twice within the last year, just over a tenth (11%) had been in hospital either three or four times in the last year, and only 4% care for someone who has been admitted five or more times.

Fig. 4.6 Number of times that the caree has been admitted to hospital within the last year



Base: 2701

Non-response: 116

Long-term carers (caring for over fifteen years) were more likely to care for someone who has not been in hospital in the last year. Over half of this cohort (55%) has cared for someone who has not recently been admitted to hospital, compared to 15% of those who have been caring for less than a year. Similarly, those people surveyed who have been caring for less than a year are the group most likely to care for someone who frequently goes into hospital; 15% of this group report that their caree has been admitted five or more times within the last year, compared to just 3% of those caring for between 1 and 5 years.

In terms of illnesses, interestingly, those suffering from addiction appear to be the most likely to be admitted to hospital on a comparatively regular basis – 41% of carers who look after people with addiction problems report that they have been in hospital three or more times over the past year. Those who are least likely to have been into hospital are those people diagnosed with learning disabilities (56% have not been admitted within the last year) and children with special needs (49% have not been admitted).

Those respondents who care for someone who has been admitted to hospital were asked the extent to which they agreed with the following statement:

‘If I had received more support as a carer, it would have prevented the person I care for being (re)admitted to hospital.’

While the majority of respondents (54%) either disagreed, or strongly disagreed with this statement, one in five (21%) felt that the hospital admittance could have been prevented in some way, had they received more support as carers.

Table 4.3 Respondents response to the statement: 'If I had received more support as a carer, it would have prevented the person I care for being (re) admitted to hospital'

	%
Strongly agree	12
Agree	9
Disagree	37
Strongly disagree	17
Don't know	26

Base: 2568

Non-response: 249

While there was little variation in terms of gender and employment status, with respect to age, the young carers (under the age of 18) surveyed were far more likely to state that they strongly agreed (22%) or agreed (19%) that the hospital admission could have been prevented, had they received more support. This is a considerable amount higher than some of the other age groups – for example of those carers over the age of 70, only 16% agreed or strongly agreed that more support would have prevented the hospital admission. While this may be indicative of the type of illness of the people that the elderly carers look after, it may be an area that warrants further investigation.

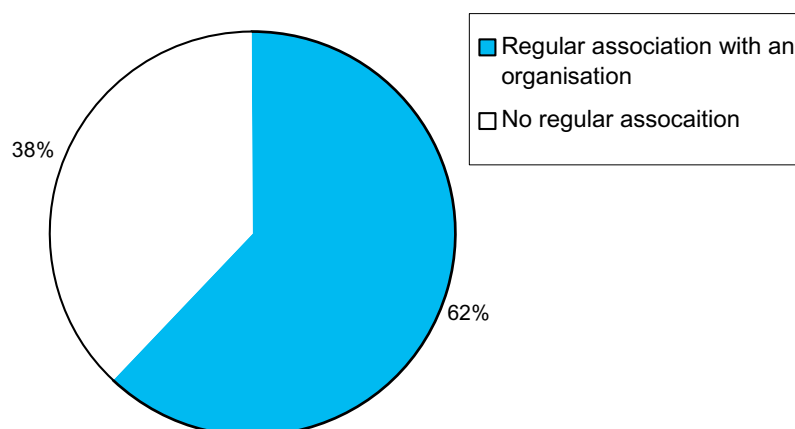
It is interesting to observe that those respondents who care for people with mental health problems, a third (33%) agree that the hospital admission could have been prevented. Similarly, those caring for people with addiction problems were also more likely to agree that both they, and the person in their care, could have significantly benefited from extra support – 42% agreed or strongly agreed with the statement; in comparison with carers of children with special needs (only 13% agreed or strongly agreed) or those with physical illnesses (18% agreed or strongly agreed). It is not possible to say whether this is because carers looking after someone with mental health issues/an addiction do not receive the same levels of support, or whether they simply require more support overall.

Interestingly, the higher the number of recent hospital admissions of the caree, the more likely the respondent is to agree that these hospital admissions could have been prevented, had the carer had been given more support. Over one in five (22%) respondents who care for someone who is often admitted to hospital (five or more times within the last year), state that they strongly agree that these admissions could have been prevented, compared to one in eight (12%) of those whose caree has been admitted once or twice. Similarly, only a third (33%) of those respondents that look after someone who is frequently admitted (more than five times) do not believe that these admissions were preventable, compared to 41% of those whose charge has been admitted once or twice, and almost half (48%) of those whose caree has not been admitted within the last year.

4.4 Local support organisations

The survey went on to ask whether those surveyed have a regular association with an organisation that support(ed) them in their role as a carer. Almost two-thirds (62%) of respondents said yes have a regular association with an organisation.

Fig. 4.7 Regular association with an organisation



Base: 3666

Non-response: 601

A significant proportion of young carers under the age of 18 have a regular association with an organisation (82%), as do those respondents over the age of 70 (67%). Those carers surveyed who fall into the 18-24 (48%) and 25-34 (50%) age groups on the other hand, are least likely to have regular contact with an organisation that support(ed) them in their role as a carer.

Women (63%) are significantly more likely than men are (52%) to have an affiliation with an organisation.

In terms of duration of caring, the findings suggest that the longer a person has been caring, the more likely they are to have regular contact with an organisation that support(ed) them in their role as a carer. Respondents that have been caring for more than 15 years are significantly more likely to have some sort of connection (65%) than those who have been caring for a shorter period.

Those who care for someone with mental health problems (68%), learning disabilities (66%) or children with special needs (66%) are significantly more likely to have some sort of contact with an organisation, than those who care for someone with an addiction (51%), or who is frail/elderly (56%).

Those respondents who have a regular association with an organisation were asked to specify the name of the organisation. Respondents provided the names of over 500

organisations and bodies. The data was allocated into the organisation types shown in table 6.1 below.

Three-quarters (75%) of respondents have a regular association with organisations specifically set up to support carers, such as Crossroads and the Princess Royal Trust for Carers. Over a quarter (28%) seek support from condition related, or national charities such as the Alzheimer's Scotland, Enable, National Schizophrenia Fellowship and Sense² and 16% of respondents have a regular association with daycentres or respite care providers, such as Homecare or Archway Respite Care.

Less than one in 10 respondents (9%) refer to their local authority or social work department as the organisation with whom they have a regular association and who supports(ed) them in their role as a carer. Additionally, less than one in 20 (4%) carers report that their support comes from the NHS, such as their local primary care trust, community psychiatric nurse or occupational therapist.

Table 4.4 Types of carers' support organisations used regularly by respondents

	%
Carers' support organisations	75
Condition related/national charities	28
Day centres/respite/care providers	16
Local authority/social work	9
NHS support services	4
Church	1

Base: 2259

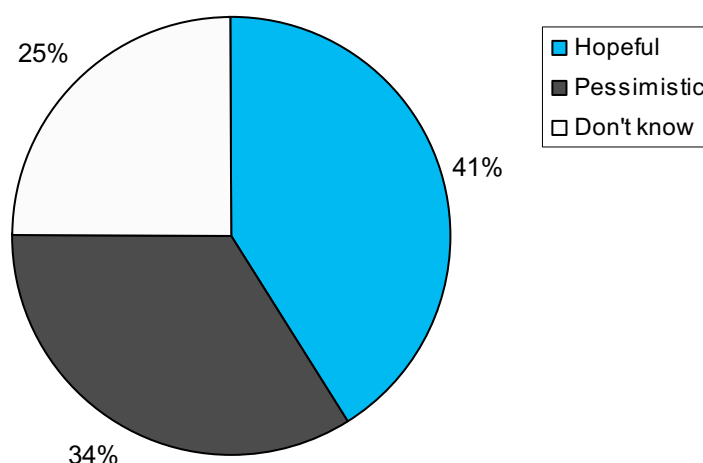
² This group may include groups that are specifically set up to support carers, if part of a subgroup of a national organisation/condition related charity.

5. Understanding the role and contribution of carers in Scotland

5.1 Perceived outlook for carers in Scotland

Carers were asked to state whether they felt optimistic or pessimistic about the future of carers in Scotland over the next 10 years. As figure 6.1 shows, encouragingly, a significant proportion of those carers surveyed (41%) do feel hopeful about the future of caring in Scotland over the next decade. Nevertheless, a further third (34%) feel pessimistic and a quarter (25%) said that they do not know.

Fig 5.1 Attitudes about the future of caring in Scotland over the next decade



Base: 4043

Non-response: 224

The findings suggest that the longer a person has been caring, the more likely they are to feel pessimistic about the future of carers in Scotland. Over a third (37%) of respondents who have been caring for over 15 years report that they feel pessimistic compared to a quarter (26%) of those who have been caring for less than a year.

Respondents with the lightest caring responsibilities (less than 10 hours a week) are much more likely to report that they feel hopeful about the future compared to those who spend over 50 hours a week caring (52% vs. 39%).

Those respondents under the age of 18 are most likely to report that they are hopeful about the future of carers in Scotland – over half (51%) said that they were optimistic about the future, compared to less than a third (31%) of those aged between 35 and 44.

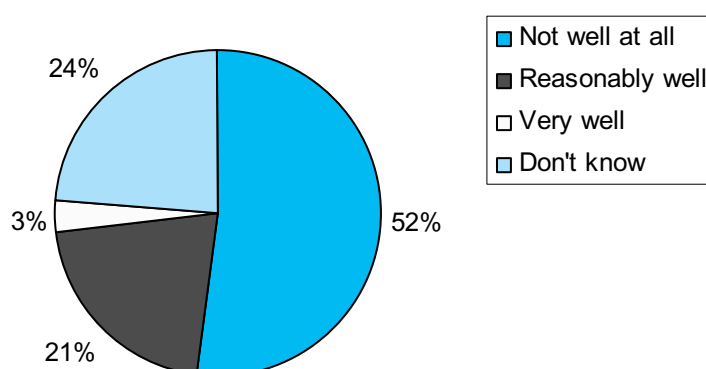
While there is little significant difference in terms of employment status, the findings do show that unemployed respondents are the most likely group to report that they feel pessimistic about the future (43%). On the other hand, almost half of the retirees surveyed (47%) state that they are *hopeful* about the future of carers in Scotland.

Further to this, those respondents who care for a child with special needs (41%) or someone with a learning difficulty (41%) are significantly more likely to report that they feel pessimistic about the future.

5.2 The Scottish Executive

Respondents were asked to rate how well they felt that the Scottish Executive understands the role and contribution of carers in Scotland. As figure 6.2 shows, over half (52%) of respondents felt that the Scottish Executive does not understand their role at all well. Just over one-fifth (21%) feel that the Executive understands their contribution reasonably well, while only a tiny minority (3%) felt that the Executive understands their role very well.

Fig. 5.2 Perception of the Scottish Executive's understanding of the role and contribution of carers in Scotland



Base: 4113

Non-response: 154

Again, the findings suggest that the longer a person has been caring, the less likely he or she is to feel that the Scottish Executive understands his or her contribution. Fifty-nine per cent of respondents who have been caring for over 15 years state that they feel the Executive does not understand their role well, compared to just over a third (34%) of those who have been caring for less than a year.

Similarly, the more care-intensive the role of a respondent is, the less likely they are to report that the Executive understands their position. Over half of those surveyed who care for over 50 hours per week (56%) report that the Executive does not understand their role at all well, compared to 36% of those who care for less than 10 hours a week.

Employed respondents are most likely to state that the Executive understands their role well, 30% of full-time workers, and 24% of part-time workers note that the Scottish Executive understands their role either reasonably, or very, well. Conversely, over three-fifths (62%) of unemployed respondents state that they do not believe the Scottish Executive understands their contribution at all well.

Respondents under the age of 18 are the most likely group to feel that the Scottish Executive understands their role well – 29% state that the Scottish Executive understands their role.

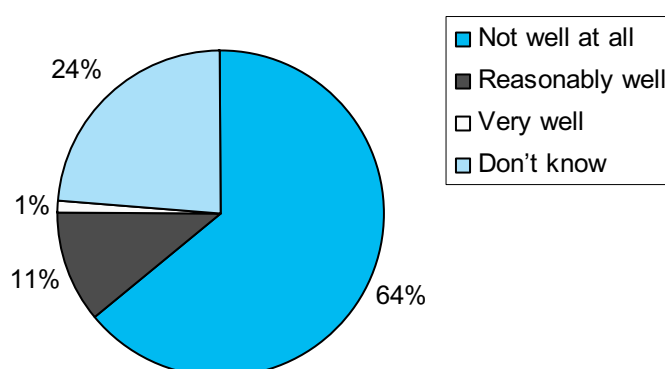
Those respondents that care for someone with learning disabilities (63%), a child with special needs (63%) or someone suffering from an addiction (63%) are more likely to report that they do not feel that the Scottish Executive understands their role or contribution sufficiently well, in comparison to someone who is caring for the frail or elderly (47%).

5.3 The Westminster Government

Respondents were also asked about their perception of the Westminster Government's understanding of the contribution of carers in Scotland.

As figure 6.3 below shows, almost two-thirds (64%) of respondents felt that Westminster does not understand the role of carers at all well; a higher proportion than for the Scottish Executive. Just over one in 10 (12%) respondents felt that Westminster has a reasonable understanding of the contribution of carers in Scotland.

Fig 5.3 Perception of the Westminster Government's understanding of the role and contribution of carers in Scotland



Base: 3837

Non-response: 430

As with the findings for the Scottish Executive above, the responses suggest that the longer a person has been caring, the more likely they are to report that Westminster has little or no understanding of the contribution of carers in Scotland; 70% of respondents who have been caring for over 15 years agree with this statement, compared to only 39% of those who have been caring for less than a year.

Again, consistent with the findings of section 6.2, high-intensity carers (i.e. those who care for over 50 hours a week) are significantly more likely to report that the Westminster government has a limited understanding of their contribution (68%).

Similarly, respondents who care for people with mental health problems (66%), learning disabilities (71%), addiction (75%) and children with special needs (70%) are significantly more likely to report that Westminster does not have a sufficient understanding of their role, compared to those who care for people with other conditions.

Furthermore, young carers under the age of 18 are most likely to state that Westminster understands their role very well, or reasonably well (24%). Carers aged between 35 and 69 years of age are significantly less likely to agree that Westminster understands their role well; 71% of 35-44 year olds report that they do not feel that their role is adequately understood.

Women (65%) are slightly more likely than men (61%) to express a belief that the Westminster government does not understand the role of carers.

Unemployed respondents (72%) are also the most likely subgroup to report that Westminster does not understand the contribution made by carers in Scotland.

Improving life for carers

Respondents were asked to identify the three most important things on a list of different issues that the Scottish Executive and/or Westminster government could do to improve the quality of life of carers. Respondents were asked to rank the three in order of importance, with 1 being their top priority and 3 being the third most important.

Table 6.1 shows the overall proportion of respondents who chose an option as a priority, irrespective of ranking, and the proportion that chose each option as their first priority. While respondents were asked to select only one option as their top priority, as the table shows, a significant number of respondents selected more than one option as their top priority.

Over half of the respondents (51%) – the largest proportion – reported that giving carers a right to regular breaks and improving upon the provision and type of respite options available would be one of the most important things that the government could do to improve their quality of life. Furthermore, over a quarter (26%) of carers surveyed chose this as their number one priority.

Financial issues also came out as an important priority – two out of every five (40%) people surveyed stated that increasing the benefits of people with support needs should be a

priority of the governments, and just under a third (32%) reported that replacing the Carers' Allowance with carers' income and pension credit was of particular importance. Over one in three (36%) of those surveyed reported that they would prefer cash payments instead of services so that carers could arrange their own care, according to their needs.

Improving information sharing and access to services has also been noted as a significant priority. A considerable proportion of respondents (17%) stated that improving the availability of information for carers should be a top priority and over a third considered it to be a priority (35%). A further third (33%) stated that improving ways of accessing services and support organisations should be an important priority.

A further 36% stated that the voluntary sector and statutory agencies should work together as full partners to ensure better coordination and over a quarter (28%) of respondents prioritised supporting those carers who work, by providing more support from employers.

Table 5.1 Ways in which the Scottish Executive and/or Westminster can help improve the lives of carers

	% that view as important	% that view as most important
Giving carers a right to regular breaks from caring and providing more and better quality respite options	51	26
Increase benefits of people with support needs	40	21
Offer cash payments rather than services so carers can arrange care according to their own needs and preferences	36	20
Ensuring that statutory agencies and the voluntary sector work better together with carers as full partners	36	16
Easier access to, and better information for carers	35	17
Better support to access services/voluntary and/or statutory support organisations	33	14
Replace carers' benefit (Carer's allowance) with carers' income and pension credit	32	21
Better support to manage the condition and/or situation of the person you care(d) for	32	13
More support from employers for people with caring responsibilities	28	12

Base: 4267

Although there are few overall differences between male and female carers in terms of government priorities, women are significantly more likely to prioritise giving carers a right to regular breaks and providing better quality respite options; 28% of women place this as a top priority for the government, compared to 21% of men.

Unemployed respondents are significantly more likely to prioritise financial issues. Almost a quarter (23%) put offering cash payments instead of services as their top priority, and 30% (compared to an average of 21%) stated that the replacement of Carer's allowance by carers' income and pension credit should be the number one priority.

Part-time workers and unemployed respondents are significantly more likely than others to prioritise better support to access services; 16% of both cohorts place this as the number one priority for the government. Similarly, both groups are also significantly more likely to prioritise giving carers a right to regular breaks (30% of part-time workers and 29% of unemployed).

Interestingly, both full and part-time workers are significantly more likely to prioritise increasing and improving the amount of support from employers; 17% of the full-time and 18% of part-time respondents surveyed place this as their top priority.

In terms of intensity of caring, respondents that care for over 50 hours a week on average, are significantly more likely to state that giving carers a right to regular breaks is the most important priority. Almost a third (32%) stated that this should be the top priority for the government, compared to 13% of those people who care for less than 10 hours a week.

High intensity carers are also significantly more likely to place financial issues amongst their top priorities compared to those surveyed who have less care intensive roles. One in four (25%) place increasing the benefits of those people with support needs as the top priority, a further 22% cite offering cash payments rather than services, and just under a quarter (24%) chose replacing Carer's Allowance with pension credit/carer's income as their most important government priority.

Those carers surveyed that have been caring for a long period of time (over 15 years) are broadly similar to those with high intensity caring responsibilities. Most significantly, a third of long-term carers (33%) place giving carers a right to regular breaks as their number one priority. Furthermore, almost a quarter (24%) state that replacing Carer's allowance is a top priority, and the same proportion (24%) prioritise the increase of benefits to people with support needs.

Further to this, respondents were asked to describe in their own words what needed to change in order to make life better for carers in Scotland. We have grouped the responses to this question into a number of themes as detailed in table 6.2 overleaf. Each theme is also illustrated with verbatim quotes from respondents.

Financial issues

Almost one in five respondents (19%) noted improvements to finance as one of the ways in which their quality of life could be improved. Respondents' main concerns were the issue of both increased and fairer allocation of benefits and allowances. Other key issues included paying carers some sort of income and increasing the amount of funding for services.

'I think the government understands what an important job carers do, but they do not acknowledge this by ensuring carers are adequately financially compensated. What would happen to the NHS if all the carers suddenly disappeared?'

'I object to the fact that I don't get paid for looking after my mother. I look after my mum for over 100 hours a week so I don't understand why I don't get a payment.'

'It would be helpful if carers were given the opportunity to access direct payments.'

'We unpaid carers are not in this business to make money, but we do incur expenses. If we didn't do it, then the Social Services would have to. The main rules which apply to the benefit called Carer's allowance need to be altered to reflect this.'

Respite care

Again, carers' breaks and respite came up as a key theme. A large proportion of respondents (18%) stated that the provision of additional, improved and cheaper access to carers' breaks would help to make life better for carers in Scotland. In particular, almost one in 10 respondents (9%) mentioned the need for more flexible respite care facilities. A number of carers surveyed also raised the issue of providing financial help with holidays, activities/holidays for special needs children and increasing the number of breaks and days off for carers.

'Make access to respite easier (information/finance) and fund more respite, especially for long-term carers.'

'Respite breaks to give carers a day to themselves.'

'There should be more respite care homes for children. Our nearest is over 60 miles away and respite families are hard to come by. There is far too much paperwork involved for respite families and this puts a lot of people off.'

Advocacy services and emotional support

Another important issue raised by 18% of respondents was the need to increase advocacy services and emotional support for carers. In particular, a number of people mentioned their wish for more respect and recognition for their work, as well as increasing the level of respect shown to carers by social workers. Improving and increasing access to counselling and support services for carers, provision of alternative therapies, regular health checks and the formation of self-help groups for carers were also cited as ways in which the respondents' lives could be improved.

'Anything that makes carers feel less isolated, i.e. the occasional telephone call to let them know they are not forgotten.'

'Regular meetings with families who also are coping with similar problems.'

'Help in raising awareness of carers' needs to promote a better understanding in the community.'

External care support

One in six (17%) carers surveyed said that additional and improved external care support would help to make their life better. In particular, respondents stated that they would like more visits and support from caring professionals, and that more carers/befrienders and sitters would be beneficial.

'Need more "Care in the Community" such as trained carers and district nurses.'

'The local authority needs to employ more 'personal care' carers.'

Provision of information

A large proportion (17%) of carers surveyed mentioned the issue of improving and increasing the provision of information and advice for carers. In particular, this included ensuring that clear and up-to-date information is available on the internet and that information about potential benefits is available to carers and is better publicised, and being more proactive about supporting carers.

'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. This pack could be made up by local authorities and distributed to all surgeries in their area.'

'Provide a national register of carers both paid and unpaid, from where advice, support and information could be received automatically. At the moment, the search for advice is totally dependent on the awareness of one's GP.'

Better coordination of services

Seven per cent of carers surveyed felt better coordinated services would help significantly to improve their lives; respondents mentioned that there should be some sort of coordinating body for all care-related organisations, and that they would like a keyworker or main contact for their family/the caree.

'Less bureaucracy by amalgamating forms and visits from various members of staff where possible to avoid the repetition of work for both carers and staff.'

'Improve the communication and relationships between all parties that should and do provide support care for people.'

Practical support

One in 10 (10%) carers surveyed stated that they would like more practical support for carers. Examples include more training for carers and either providing help with paperwork or ensuring that it is easier to understand.

'Affordable help with household repairs and decorating that carers do not have the time or expertise to do themselves.'

'Less paperwork would be a start!'

Healthcare

One in 20 (5%) of those surveyed stated that improvements to healthcare would help to improve the life of carers in Scotland. In particular, respondents mentioned the need for regular home visits by doctors and the inclusion of carers in diagnosis, and increasing the numbers of primary healthcare staff and/or social workers.

'GP training should include the special needs of carers. GPs should also be encouraged to make the carer a partner in the care package.'

'I think GPs should offer more support and would suggest that they visit the person being cared for at least once a month.'

Day care centres

A proportion of respondents mentioned the need to increase and improve upon day centres and day-care services (3%), particularly with regard to making them more flexible.

'A more extensive range of services for people needing support, as opposed to one day-centre that has to accommodate the needs of 100 very different people.'

'Day care being open for longer – my father gets picked up at 10 and then he's home for 2 – that's not much of a break is it?'

Employment and education/childcare

Greater support from employers (2%) and improvements to employment laws were also mentioned, as were improvements to the education/childcare system (2%) – particularly with respect to the increased provision of special schools and more support from the local authority.

'Understanding from employer – I work as well as being a carer, and my employer does not consider this at all – I have difficulty getting time off if I need it to accompany my mother for appointments so I have to use holiday time.'

'Better local access to pre-school, mainstream and adult education services that cater for people with special needs.'

A relatively significant proportion of the carers surveyed also highlighted other forms of practical and financial help. Help with the house or home improvements was mentioned by 4% of respondents as something that would make their life better; a further 3% mentioned

assistance with transport needs, and 1% mentioned the need to improve disabled access, particularly in city centres (1%).

‘Shop mobility places nearer bus stations to enable non-car users to access their premises.’

Table 5.2 What needs to be changed to improve the lives of carers in Scotland

	%
Financial/resources	19
Respite/carer breaks	18
More advocacy/emotional support for carer	18
More/better external care support	17
Communication/information/advice	17
More practical support for carer	10
Better coordinated/less bureaucratic services	7
More/extended specialist healthcare (i.e. medical/nursing)	5
Easier access to care/more flexibility	4
Housing needs	4
Day-care/day centres	3
Transport	3
Employers	3
Better assessment of needs	3
Childcare/education	2
Better trained staff	2
More recreational activities	1
Improve hospital care	1
Improved disabled access	1
Others	4

Base: 1720

Non-response: 2547

Overall, there is little significant difference between the responses in terms of age, gender, work status, intensity of caring, and the condition of the caree, highlighting the broad set of needs of respondents and the complex nature of caring.

The responses varied most in terms of how long each of the carers surveyed had been caring. Respondents that have been caring for a long time are significantly more likely to state that they would benefit from better emotional support for the carer (21%), particularly with respect to improving the recognition of the carer’s role (11%).

Those people who have been caring for less than a year are most likely to express a need for better information and advice services – 30% state this as something that would improve their life.

Over one-fifth (22%) of respondents that have been caring for over 15 years state that they would benefit from improved financial assistance – compared to 11% of those who have been caring for less than a year.

The findings also suggest that the longer a person has been caring, the more likely they are to state that improved carers' breaks would make their life better. One-fifth of respondents (21%) who have been caring for over 15 years stated that this would help improve their life, compared to just 13% of those who have cared for less than a year. Similarly, heavy intensity carers are significantly more likely to express a preference for improving carers' breaks – 22% of respondents who care for over 50 hours a week stated that this would help make their life better.

In terms of gender, one in five women (20%) surveyed stated that better carers' breaks would help improve their quality of life, compared to just over one in 10 men (11%). Women (19%) were also slightly more likely than men to state that there needs to be more advocacy/emotional support services for carers.

Interestingly, one in 10 people working full-time (10%) stated that employers should give more support and improvements should be made to employment laws. Almost a quarter (23%) of part-time workers surveyed stated that some sort of improvement should be made to carers' breaks, compared to 13% of full-time workers. Retirees were the least likely cohort to state that improvements to financial/resource issues would help to improve their life – only 6% stated this as a need, compared to 22% of full- or part-time workers, or the unemployed.

With respect to the condition of the caree, those respondents caring for someone with special needs (3%), or a child with learning difficulties, were most likely to state that increased/improved provision of schools would help to improve their quality of life.

Respondents were asked about how specific organisations could help improve the lives of carers. Each person surveyed was asked to name up to three organisations, and then describe the ways in which they could each improve the quality of life for carers. Below we try to analyse where respondents feel the main responsibilities for the overall issues should lie.

Local authorities

A significant proportion of respondents (17%) named their local authority and social work department as someone who would be able to provide some sort of support. The main issue raised was the need for the local authority to improve the level of communication and advice it provides; in particular, providing more meetings, accurate database information and regular newsletters.

A large proportion of respondents stated that their local authority and social work department could improve upon, and increase the provision of external care support. The main issues here were the need for more appointments, and more hours of care per week. A significant proportion also mentioned the need for local authorities and social work

departments to provide better advocacy and emotional support for the carer; respondents particularly focused on the need for more respect to be shown.

Consistent with other findings, respite care was one of the key issues, and respondents felt it was largely the responsibility of their local authority/social work department. Specific issues included making more respite care available, introducing sitters when the carer has hospital or dental appointments and the ability to book respite care in advance.

NHS

One in 12 people surveyed (8%) referred to the National Health Service, including CPNs, rehabilitation units and occupational therapists, as a provider that could help improve services for carers. A large proportion of respondents felt that responsibility for providing more specialist healthcare should lie with the NHS, particularly with regard to reducing both the changeover of staff and waiting times for the person being cared for.

As with local authorities and social work departments, a large proportion of people felt that the NHS should improve the level of communication and advice it provides, again particularly with respect to providing accurate information. A number of respondents also stated that it should be the responsibility of the NHS to provide improved and increased numbers of carers' breaks, and more advocacy and support services for carers.

Carers organisations

Five per cent of respondents mentioned carers organisations. These could help particularly by focusing on advocacy and providing emotional support, and helping provide communication, information and advice to carers.

Condition related charities and/or voluntary organisations

A further 3% mentioned condition related charities and/or voluntary organisations. The main issues that respondents felt they could change included improving their levels of communication and advice – particularly with respect to providing more meetings and helping with carer breaks.

Day-care centres

Two per cent also mentioned day-care centres as helping to improve the lives of carers, mainly focusing on improving access to carers' breaks and providing more centres.

Life after caring

Those respondents who indicated that they are former carers were also asked to think about what support would have been most helpful when they stopped being a carer.

As outlined in table 6.3 below, counselling was the most frequently discussed support mechanism that would have benefited respondents. Over half (52%) of all the respondents felt that this would have been most helpful.

The next most frequently mentioned form of support was no immediate change in their benefits during the adjustment period immediately following the end of their caring duties (33%).

Over one in 10 (11%) would have liked assistance in the task of re-entering employment.

Smaller proportions said that no immediate change in housing entitlements (7%); support to re-enter education or training (6%); or financial advice (3%) would have been the most helpful support.

Table 5.3 Support that would have been most helpful when you stopped being a carer

	%
Counselling	52
No immediate change in benefits	33
Support to re-enter employment	11
No immediate change in housing entitlements	7
Support to re-enter education or training	6
Financial advice	3
Other	4

Base: 537

Those carers who had cared for someone with mental health problems (65%) and those in full time employment (64%) were more likely than other subgroups to say that they would have benefited most from counselling.

Those working part time (28%) or who are unemployed (26%) were the most likely to indicate that support to re-enter employment would have been most helpful to them.

6. Specific groups of carers

6.1 Young carers

Young carers represent a small proportion (2%) of the overall sample; the vast majority of which are currently caring – 86% of under-18 year olds surveyed describe themselves as a current carer under the age of 18.

Young carers are most likely to care for either a sibling (47%), or a parent (51%), and are least likely to be the main carer (61%). While carers under the age of 18 tend to spend less time caring than the older carers surveyed (34% spend less than 10 hours caring a week), a significant proportion (21%) spend between 30 and 39 hours a week caring – this is a high proportion, particularly if the carers are still at school.

Those carers surveyed under the age of 18 are most likely to say that their health has not been affected as a result of their caring responsibilities (28). However, almost two-thirds (62%) report feeling tired, and 28% report having felt depressed.

Almost half of the young carers surveyed (49%) state that caring has not affected their personal/social life – significantly higher than the other age groups. However, almost a fifth (19%) of carers state that their education has been affected as a result of their caring.

The young carers surveyed seem to have a good level of support – a significant proportion of respondents under the age of 18 have a regular association with an organisation (82%).

Respondents under the age of 18 are also the most likely to report that they are hopeful about the future of carers in Scotland – over half (51%) said that they were optimistic about the future. Furthermore, young carers are also more likely than older carers to feel that the Scottish Executive (29%) and Westminster (24%) understand their role well.

However, with respect to the carer assessment – young carers are significantly less likely to have been informed of their right to a carer assessment (only 37% have been told about it), and an even smaller proportion (28%) have actually had an assessment. Encouragingly, of the respondents who have had an assessment, all (100%) reported that it has made a difference.

Of some concern is the significantly high proportion of young carers who believe that the person they care for would not have been admitted to hospital had their carer been given more support. Forty-four per cent of young carers surveyed agreed or strongly agreed that the admission could have been prevented had they had better support; almost double that of the overall sample (21%). Given that a high proportion of young carers (71%) look after someone who has been admitted to hospital, this is worrying.

6.2 Carers who work

The vast majority (72%) of the sample are not in paid employment – with 41% being retired, a quarter (24%) are of working age but not seeking work, 3% are unemployed but seeking work, 3% are students and 1% do voluntary work. Of those respondents who are in some kind of paid employment (28%) – 12% work full time, 13% work part time, and 3% are self-employed.

Those respondents who are working either full or part-time, or are unemployed, were significantly more likely to have experienced some sort of negative effect on their social and personal life as a result of being a carer, compared to those who are retired.

Part-time workers seem to have experienced the most negative impact upon their career with almost half (47%) saying their career has been affected by their role as a carer, compared to 39% of full-time workers and just 11% of retirees. Part-time workers may be most affected by their caring duties because of having to work a reduced number of hours per week in order to fulfil their caring roles.

The work status of respondents also seems indicative of the likelihood of a carer assessment occurring – those carers surveyed who work full or part-time are significantly less likely to have had a carer assessment than those who are unemployed or retired. Only 23% of full-time workers, compared to 35% of retirees, have had a carer assessment. Yet those people who are working full-time (66%) were significantly more likely than others to report that once they had received an assessment it had made a difference.

Former carers were also asked to think about when they stopped being a carer and what support would have been most helpful. Those working part time (28%), or are unemployed, (26%) were the most likely to indicate that support to re-enter employment would have been most helpful to them. Those in full time employment (64%) were more likely than other subgroups to say that they would have benefited most from counselling.

Encouragingly, when asked to describe their employers understanding of, and willingness and ability to support, a person's caring responsibilities, over half of full-time (53%) and part-time (58%) workers described it as either good or very good.

Nevertheless, a significant number of full-time (23%) and part-time (18%) workers described their employer's understanding as either poor or very poor.

Table 6.1: Employers understanding of, and their willingness and ability to support, a person's caring responsibilities

	Full time workers %	Part time workers %
Very good	31	32
Good	22	26
Average	25	25
Poor	14	9
Very poor	9	9

6.3 Male and female carers

The Care 21 survey has highlighted variations among male and female carers.

There are significantly more women in the sample compared to men (74% women vs. 24% men), consistent with what we already know about the higher proportions of women with caring responsibilities.

Men and women are also shown to be in different caring situations, as illustrated in table 7.4 below. Women are much more likely to care for one of their children, or a parent, compared to men who are significantly more likely to care for their partner/husband or wife.

Table 6.2: Differences between men and women in their caring situations

Caring situation	Male carers %	Female carers %
Caring for a partner/husband/wife	65	35
Caring for a son or daughter	12	35
Caring for a parent	18	24
Caring for someone with a physical illness	52	41
Caring for someone with a learning disability	11	25
Caring for a child with special needs	6	17

Women are slightly more likely to have been caring for longer than men – 26% of women have been caring for over 15 years, compared to 18% of men. There is no significant difference between the sexes in terms of intensity of caring.

Although broadly the same, men and women are likely to have slightly different care roles. Women are much more likely to help with emotional support and speaking up for the person who is being cared for, while men are much more likely to help with physical tasks.

Women are *significantly* more likely than men to experience a negative effect on their health and well-being as a result of their role as carer, particularly with regard to depression

and feelings of stress. Double the proportion of men (8%) than women (4%) report that their health has not been affected by their caring role.

Furthermore, women are again *significantly* more likely than men to experience a negative impact on their social life as a result of their role as carer. In particular, feeling isolated and forcing other aspects of their family life to take a back seat were the main issues women reported. Fifteen per cent of men reported no change in their personal/social life, compared to only 9% of women.

This is despite the fact that women (63%) are significantly more likely than men (52%) to have a regular association with an organisation that support(ed) them in their role as a carer.

In terms of the overall priorities for men and women, it is interesting to observe that double the proportion of women (20%) surveyed reported that respite/carers' breaks needs to improve in order to make life better for carers in Scotland, compared to male respondents (11%). This is a significant finding, and may perhaps be linked to the fact that men tend to care for their partners, whereas many female carers surveyed care for other family members, such as a son or daughter, as shown in table 7.2.

A higher proportion of women prioritise more advocacy and/or emotional support for the carer. One in five (19%) women surveyed stated that this was something that needed to change in order to improve the lives of carers, compared to one in seven (15%) men.

Men on the other hand, are slightly more likely to prioritise financial or resource issues than women, with 22% specifying finance related issues, such as allocating benefits more fairly, compared to 19% of women.

However, it should also be observed that overall the key issues for both sexes are of roughly similar proportions, in terms of what needs to be changed to improve the lives of carers in Scotland.

Table 6.3: Differences between men and women in terms of what needs to be changed to improve the lives of carers in Scotland

	% Male respondents	% Female respondents
Financial/resources	22	19
Respite/carer breaks	11	20
More advocacy/emotional support for carer	15	19
More/better external care support	18	17
Communication/information/advice	17	17
More practical support for carer	8	10
Better coordinated/less bureaucratic services	7	7
More/extended specialist healthcare (i.e. medical/nursing)	4	5
Easier access to care/more flexibility	3	4
Housing needs	3	4

Table 7.4 outlines the differences between men and women in terms of the ways in which the governments can help to improve the lives of carers. Again, as with table 7.3 above, overall there are few differences between the different priorities of men and women.

However, once again, consistent with previous findings, some differences do exist in terms of respite care. Significantly more women than men place this as the most important priority for the government.

Again, men are more likely to prioritise financial issues than women; 25% of men place increasing the benefits of people with support needs as the number one priority for the government, compared to 21% of women. While the reasons behind this are not clear, one explanation could be that, a larger proportion of men may have had to give up work to undertake their caring responsibilities, and therefore, in many cases the household has lost access to the main earnings, making financial issues more important.

Table 6.4: Differences between men and women in terms of the ways in which the Scottish Executive and/or Westminster can help improve the lives of carers

	% Male respondents	% Female respondents
Giving carers a right to regular breaks from caring and providing more and better quality respite options	21	28
Increase benefits of people with support needs	25	21
Offer cash payments rather than services so carers can arrange care according to their own needs and preferences	21	20
Ensuring that statutory agencies and the voluntary sector work better together with carers as full partners	15	16
Easier access to, and better information for, carers	15	18
Better support to access services/voluntary and/or statutory support organisations	14	14
Replace carers' benefit (Carer's allowance) with carers' income and pension credit	20	22
Better support to manage the condition and/or situation of the person you care(d) for	13	13
More support from employers for people with caring responsibilities	11	13
Others	2	1

6.4 High intensity carers

High intensity carers constitute a large proportion of the sample – almost two-thirds (63%) of respondents state that they currently (or in their previous capacity as a carer) spend at least 50 hours a week looking after the main person they care for.

These respondents are much more likely to have been caring for a long period of time; almost three-quarters (71%) of carers who spend at least 50 hours a week caring have been caring for over five years and 17% have been caring for over 20 years. High intensity carers also tend to be older – half (49%) of the people caring for at least 50 hours a week are over the age of 60.

High intensity carers are most likely to care for a partner than those who have less intensive care responsibilities – half the cohort (50%) care for their partner/husband or wife.

Any future initiatives to support high intensity carers need to embrace the wide variety of responsibilities that these carers have. Respondents who spend over 50 hours a week caring are without exception significantly more likely to undertake a variety of different duties on behalf of the carer, including providing practical help, emotional support, personal care and financial help.

It is important to observe that respondents with heavy, care-intensive roles are far more likely to experience poor health as a result of their care responsibilities: 88% reported

feeling tired, two-thirds (66%) stated that they have felt depressed, and three-quarters (76%) report a general feeling of stress. Only 4% stated that their health had not been affected in any of the ways listed. For each of the symptoms listed (see section 4.1), the longer a person spends caring per week, the higher the proportion of people affected by each, illustrating that the more intense the caring experience, the greater the level of support needed.

Furthermore, high intensity carers are much more likely to have experienced some sort of impact upon their social/personal life as a result of their caring responsibilities. In particular, over four-fifths (83%) stated that they have suffered from a lack of free time, while two-thirds (67%) have had to give other aspects of their family life a back seat. Again, as with health and well-being, only 8% stated that their personal life has not been affected.

The findings from this survey suggest that people who have very time-intensive care responsibilities are no more likely to have been informed of their right to, or been given, a carer assessment than those who have a less intensive role. However, high intensity carers are more likely to have had a carer assessment (36%) than those who have been caring for shorter periods.

Almost a third (32%) of high intensity carers surveyed put giving carers a right to regular breaks from caring as their top priority in terms of how the government could improve the lives of carers in Scotland. Furthermore, financial issues tend to be of more importance, with one in four high intensity carers (25%) placing increasing the benefits of those people with support needs as their top priority (25%), and a further quarter (24%) choosing to replace Carer's Allowance with pension credit/carer's income as the most important government priority.

Finally, it should be noted that the more care-intensive the role of a respondent is, the less likely they are to report that the Scottish Executive understands the role of carers. Over half (56%) report that the Executive does not understand their role at all well, while 68% state that Westminster does not understand their role sufficiently well.

7. Positive aspects of caring

Respondents were asked to describe in their own words the positive and rewarding aspects of being a carer. The vast majority of responses were centred on doing the best by the caree – whether it be making them feel safe and comfortable, helping them become independent or enabling them to remain in their own home.

Almost one in five (19%) respondents stated that doing their best for a loved one was a positive or rewarding aspect of their caring responsibilities.

‘Knowing your cared-for person will get no better help than they get from you.’

‘She is my partner and soul mate of 33 years, so I simply want to care for her.’

One in six (16%) people surveyed felt positive about the fact that they had helped make it possible for the caree to remain at home.

‘Being able to keep someone in their own home, rather than having to go into a home.’

Over a tenth of respondents (12%) reported that helping to make the caree happy, comfortable and safe was one of the rewarding aspects of being a carer.

‘I enjoy seeing my brother happy and seeing him learn new things and growing up.’

A similar proportion (12%) noted that it was about providing help, support and care to the person being looked after.

‘The only positive is that you know you have done all you can to support them.’

A significant proportion of respondents (7%) noted that, for them, it was about giving the person who was being cared for a better quality of life.

‘To know that you are doing your best to give your family member as good a quality of life as is possible.’

Smaller proportions of respondents reported that caring provides them with a sense of achievement; or made them feel good, and/or provided them with peace of mind and a sense of satisfaction; or that caring to them was about returning care given to them in the past.

‘Sometimes there is some sense of purpose or achievement. There is a feeling of being important.’

‘The great sense of pleasure and pride when she is successful at school and we can then know that we have done our best’

‘Being able to support the person who supported you in childhood – feeling of doing something in return.’

Perhaps unsurprisingly, respondents gave a wide range of answers as to what they think are the positive aspects of caring, other aspects discussed included learning new skills, saving the government money, helping the caree to maintain their moral dignity, and meeting people that they would not otherwise have met.

Those respondents with intensive care responsibilities (over 50 hours per week) are most likely to report that a positive or rewarding aspect of caring is doing the best by a loved one (21%), while those who care for less than 10 hours a week are significantly more likely to state that they find that the progress being made is rewarding (7%) or that they are helping their relative to remain independent (7%).

Respondents who have been caring for a long period of time (over 15 years) are the most likely group to state giving and receiving love as a positive and rewarding aspect of caring (8%). Respondents who have been caring for a smaller amount of time (less than one year) are much more likely to state that it is about doing your best by a loved one.

In terms of gender, women tend to be more likely to focus on the practical side of caring as a positive aspect: 17% of female carers stated that enabling the caree to live in their own home, and a further 13% reported making them feel happy, comfortable and safe, as positive elements of their caring (compared to 13% and 8% respectively). Men tended to outline the slightly more dutiful elements; 21% stated that doing their best by a loved one was a rewarding part caring, as well as giving them a better quality of life (10%). This compares to 18% and 6% respectively for women.

Interestingly, the older the respondent, the more likely they are to state that positive aspects of caring are about enabling the person being cared for to remain in their own home. Over one in five (21%) respondents over the age of 70, compared to just 2% of those under the age of 18, state this as a positive aspect of their caring responsibilities.

Appendix 4:

Voices of carers 2 – Report on focus groups and interviews with unpaid carers in Scotland

1. Executive summary

Objective

In September 2004, Care 21 commissioned OPM® to undertake research into the needs of unpaid carers over the next 10 years, as part of its drive to provide more responsive services. A significant part of this exercise involved talking to carers, to establish their views on current levels of support and future needs. Care 21 also commissioned a separate piece of research into the future needs of carers with mental health problems and learning difficulties. The findings of both of these research exercises are synthesized and presented here.

Overall approach

We adopted a qualitative methodology for this research, gathering the views of specific groups of carers in urban and rural locations. In total, we spoke to 151 unpaid carers, through ten focus groups with a total of 79 participants, three mini-groups with a total of 13 participants and 59 in-depth individual interviews. Carers' experiences varied widely, in terms of who they cared for, why care was required, the time they spent caring, the tasks they carried out, the duration of caring and their background, age and general health.

Key findings

Co-ordination of care services

- There were mixed experiences of how successful statutory services were in meeting the needs of carers; successful services appeared to depend heavily on the personal relationships and rapport between professional staff (including doctors, social workers) and the carers themselves. Experiences also varied by location.
- Elderly and black and minority ethnic (BME) carers tended to have little contact with a wide range of services, because care was perceived as a duty.
- GPs act as the first point of contact for many carers, and therefore their proficiency in connecting the carer with wider support services is crucial.
- Carers reported that co-ordination of services was poor where it concerned acquiring equipment and alterations / adaptations in the home.
- The co-ordination of services during the transition from caring for a child to caring for an adult was perceived as poor.
- Carers perceived a lack of co-ordination between the management of health service and local authority social work services budgets.
- Mental health was seen as not being taken seriously enough by the medical profession. Carers with mental health problems and learning difficulties had difficulty articulating their needs.

- There was universally high praise for the work of the voluntary sector, which tended to offer support through caring support groups, information provision, advice on legal matters and rights, practical support in daily life and befriending schemes.

Provision of information

- Carers had widely differing opinions about the provision of information.
- Carers could not access information from any central point, such as GPs. Many discovered information by chance or through word-of-mouth.
- Carers found it difficult to access information on benefits.
- Young carers needed conditions and situations to be carefully explained.
- Information provision is not a one-way process. Carers called for recognition as equal partners.
- In some cases, medical confidentiality issues conflicted with the ability to care.

Effectiveness of policies to support carers

- Overall, carers were dissatisfied with the level of support and recognition they received from the government.
- Depending on their age, carers had different perceptions of the effectiveness of policies to support them. Elderly carers felt there was little consideration for their situation, particularly once they reached pensioner status. Young carers needed tailor made support, offering the opportunity for breaks from caring where they had chosen to care, and recognition that they are young people first and carers second, within a family setting.
- Carers with mental health problems and learning difficulties had complex needs, and services were not tailored around identifying these carers and supporting their needs.
- The financial security of many carers was felt by many to be at risk, in particular when they had cared for most of their employable age.
- Carers felt they did not receive adequate training to fulfil caring tasks safely.
- Respite care provision was not always dependable, suitable and adequate.
- Carers in rural areas felt little attention was given to accessibility of services, such as transport.
- Those caring for people with less 'visible' conditions, such as depression or alcoholism, felt very unsupported by the system.
- Carers were not supported in practical ways, for example help around the home and with fuel bills.

Employer-based support for carers

- The vast majority of participants in the study were women. Many of them worked part time and, in particular, in traditionally low paid occupations in which women tend to be over-represented.

- Employment and career trajectories were often shaped by caring responsibilities, or decisions were made by carers to stay in a particular job because the organisation of work fitted into the rhythms of caring and family life.
- Male participants who shared the caring responsibility with their partners tended to work full time. However, when they had sole responsibility, balancing full time work and care was impossible.
- The high cost of childminders cancelled out the financial advantage of working for parents who had children with special care needs.
- Only a minority of employers in the study seemed to be supportive of carers, and most of this support was informal, on the basis of goodwill, where the employee was a friend of the employer or a good working relationship had developed over a number of years.
- Many carers emphasised that work was an important way of enhancing their overall wellbeing. Working was perceived as a particularly life-enhancing experience for carers with mental health problems and learning difficulties, and they wanted to be better supported to find suitable employment.

Education

- The issue of education only affected young carers in the study. The impact of caring manifested itself in absences from school in order to fulfil responsibilities, the inability to develop close relationships with school peers because of caring commitments and embarrassment, and the inability to focus on schoolwork because of preoccupation with problems at home.
- Some schools were very supportive of young carers, although some young carers had had their trust broken by school staff and other professionals.
- Young carers' future career plans were often affected by continuing caring responsibilities.

Carers' health: Psychological and emotional support

- A common concern was the lack of support to help carers deal with the psychological and emotional demands of caring.
- Carers often expressed feeling isolated and depressed, and the lack of counselling services was a common experience.
- This lack of emotional support services was seen as linked to the *invisibility* of carers; that is, services tend to focus on the person being cared for, leaving carers out of the equation.
- Carers needed counselling or independent services, on an individual basis as well as family counselling, to relieve them of some of the burden of caring.
- Voluntary organisations and carer support groups were seen as important in both urban and rural areas, providing much-needed support.
- The lack of provision meant that carers had to establish their own psychological support mechanisms, by informally getting together with other carers.
- A feature of counselling and psychological support services was the lack of BME participation in mainstream groups, and the particular isolation of young BME carers.

- Carers with mental health problems experienced the stigma associated with mental health issues, and felt particularly isolated because of unsympathetic statutory services and the lack of people to talk to outside the mental health community.

Contact with care professionals

- Overall experiences and perceptions of social workers were negative. It is not a finding of this research that these perceptions were negative relative to other care professionals as a comparison of the perceived roles and responsibilities of different care professionals, and their effectiveness in providing support was not a focus of the research.
- GPs were seen by many carers as key, as the first point of contact.
- Social workers were generally seen as overworked, untrustworthy, unprofessional and lacking in knowledge and empathy of carers' situations, though some good experiences were cited.
- There was a strong perception that social work departments are under-resourced and under-staffed.
- Positive experiences with social workers followed from a long-term relationship between carer and social worker.
- Carers' Assessments were seen as not working, not taken seriously and offering empty promises.
- Social workers were perceived as able to fulfil an important role in information provision.

Priorities for carers over the next 10 years

We asked carers about how they see the future over the next 10 years, and what they would like to see in place to support carers. Most carers found it difficult to think about the future, first because they felt that the current level of support was not satisfactory, and secondly because thinking about the future was daunting – that many carers feared for their own health, and therefore their continued ability to provide care.

Within this context, carers expressed the view that the concerns and difficulties they had currently would multiply and become more acute as they became older. However, they identified a number of priorities for enhancing access to support services, as well as the delivery of support services. The following are key themes which emerged from an analysis of what they told us. These are set out below, are not in any order of priority:

1. *Recognition of carers*

The role of carers should be properly recognised. For some this means caring being regarded as an occupation and supported accordingly by the Government, both financially and other support. Others expected the same rights and access to support that paid care staff receive, such as free health checks, inoculations, health and safety training. Carers expected to be treated as equal partners in the caring situation.

2. *Transformation of care models and mainstreaming*

Mainstream support services need to ensure equality of service provision and the cultural appropriateness of provision by making BME communities central to the planning, promotion and delivery of care support services.

3. *Funding for voluntary and community organisations*

Carers saw a need for voluntary agencies to have more secure funding to enable them to continue playing an important advocacy role on behalf of carers, thus helping carers to identify and access services, as well as to provide essential emotional and practical support.

4. *Care breaks and other support services*

Access to respite and short breaks, and the quality of these services when accessed was perceived by most to be very poor. More support needs to be made available to assist carers in the next ten years, including care breaks, outings for the people they care for, and assistance in the home customised to the needs of the whole family rather than determined by statutory agencies. Respite care should make provision for people of different ages and with different conditions.

5. *Future planning for carers of children*

More effective forward planning for the care needs of children with disabilities is needed, so that parents know what will become available from the outset, rather than being faced with a situation where there is nothing in place to enable them to cope with the transition from caring for a child to caring for a young adult.

6. *Targeting of information*

Information needs to be targeted more effectively at all groups of carers and the wider public, through schools, community centres, doctors' surgeries, churches, mosques, local radio and the ethnic press; in various community languages; and through better co-ordination between carers' organisations and statutory and voluntary agencies.

7. *Counselling*

Carers need more counselling services, on an individual basis or as families, to help children as well as parents cope with the demands of caring.

8. *Benefit entitlements*

Carers experienced the benefits system as complicated. Bureaucratic obstacles to carers claiming financial assistance need to be removed, and carers need more assistance with form filling and transparent advice on benefit entitlements.

9. *Bilingual workers*

Services should employ more bilingual workers, to provide the necessary support to BME communities, either in their own homes or in community-based establishments.

10. *Support for elderly carers*

Elderly carers need more support in the home to enable them to continue in their caring role if their own health deteriorates, to prevent the person they are caring for from having to go into a residential establishment.

11. *Support for young carers*

Young carers need more support and motivation, in the form of informal breaks and carers' projects and wider recognition of their contribution.

12. *Support for carers with mental health problems and learning difficulties*

Carers with complex needs need more support to help them access services in a fair way. There is also a need to continue to target the prejudices of the rest of society and perceptions of mental health problems.

13. *Assistance with fuel bills and other practical support for carers*

All carers, not just the elderly, need assistance with fuel bills and other practical support, since caring often means being in the home all day with the person being cared for.

14. *Island and rural carers*

Carers who do not live on the mainland or who live in rural areas need more support services.

15. *Consultation and partnership with carers*

Consultation should take place with carers who are actually doing the work, not carers' organisations, because a limited number of carers actually engage with these organisations due to a lack of knowledge.

2. Methodology

Our approach was qualitative and based on the open-ended narrative exploration of a number of key themes agreed with Care 21. The stories of carers were collected through focus groups, group interviews and in-depth individual interviews. The research was conducted across five regions, i.e. the Highlands, Edinburgh, Glasgow, Fife and North and South Lanarkshire, so we were also able to explore how unpaid carers' experiences differ in urban and rural areas.

The experiences of carers are diverse: they vary widely in terms of who they care for, their ages, their backgrounds and the length of their caring experience. To account for these differences, we engaged in specific consultation with carers from BME groups, elderly carers, young carers and carers with mental health issues and learning difficulties. The report emphasises the main issues of relevance to these different groups.

A semi-structured topic guide, appended to this report, guided the focus groups and in-depth interviews with carers. In the case of carers with mental health issues and learning disabilities, the topic guide was slightly adapted according to the challenges posed by engaging these groups of carers. The purpose of a semi-structured topic guide was to ensure that the discussion covered the themes agreed with the Scottish Executive, but also to provide flexibility for incorporating issues specific to respondents in different situations.

2.1 Focus groups

Ten focus groups were initially set up, comprising carers across a range of cohorts, i.e. young carers in urban and rural locations, employed carers in urban and rural locations, unemployed carers in urban and rural locations, elderly carers in urban and rural locations, and black and minority ethnic carers.

The organisation of the focus groups was as follows:

- Group 1, BME carers, Glasgow
- Group 2, BME carers, Edinburgh
- Group 3, elderly carers, Glasgow
- Group 4, elderly carers, Nairn
- Group 5, young carers, Irvine
- Group 6, young carers, Isle of Skye
- Group 7, carers in paid employment, Edinburgh
- Group 8, carers in paid employment, Helmsdale
- Group 9, carers not in paid employment, Dumfermline
- Group 10, carers not in paid employment, Dingwall

Table 1 below provides a breakdown of the gender of participants in each of the focus groups.

Table 1: Number and gender of participants for focus groups

Focus group	Gender		Total
	Female	Male	
Group 1	8	2	10
Group 2	6	3	9
Group 3	6	4	10
Group 4	6	3	9
Group 5	3	1	4
Group 6	5	3	8
Group 7	8	1	9
Group 8	4	0	4
Group 9	6	0	6
Group 10	6	4	10
Total	58	21	79

In total, 79 carers took part in the focus groups. Participants were selected through an independent recruiter, to ensure that we did not only engage carers who were supported by specific voluntary and statutory organisations.

2.2 Mini discussion groups

We also conducted three mini-groups, two with BME carers with language support needs and one with carers with learning disabilities. A total of 13 carers took part in mini discussion groups.

The mini discussion groups were held in Glasgow and Edinburgh, and were as follows:

Group 1, BME carers with language support needs, Edinburgh

Group 2, BME carers with language support needs, Edinburgh

Group 3, Carers with learning disabilities, Edinburgh

Table 2 below provides a breakdown of the gender of participants in these groups.

Table 2: Number and gender of participants of mini-groups

Focus group	Gender		Total
	Female	Male	
Group 1	3	0	3
Group 2	4	0	4
Group 3	4	2	6
Total	11	2	13

2.3 In-depth interviews

In-depth interviews with carers with mental health issues and learning difficulties were conducted across the Highlands, Glasgow, Edinburgh, Fife and North and South Lanarkshire. The majority of interviews took place in the central belt of Scotland, in Glasgow, Edinburgh and the surrounding areas of East Kilbride and Tullibody. Of the 59 respondents, 42 were women and 17 were men. Respondents for these interviews were contacted through a range of sources, including returns of the Carer Survey sent out as part of this project, carers' support organisations, and through snowballing. Leaflets outlining the aims of the project were also circulated at events, inviting people to take part in the research.

Carers with mental health issues and learning difficulties were particularly challenging to identify. Carers with these types of special needs are particularly isolated and difficult to locate. Even with the help of advocacy organisations, people were at times unable or unwilling to take part in the project even when confidentiality was assured. Through the fieldwork, it became apparent that carers with mental health issues and/or learning difficulties were not keen to talk about their experiences with people they considered strangers. In order to manage this issue we made efforts to ensure that participants felt comfortable and safe in the interview or group environment, with additional access to advocacy organisation staff or other support throughout the interview and discussion group process.

3. Findings

3.1 Introduction

It is inevitable that the situations of unpaid carers will be very similar in some ways and very different in others. Some groups of carers, such as BME, elderly and young carers, have particular needs and experiences, but also share experiences with other carers in relation to general levels of support and the quality of service provision. The following sections discuss unpaid carers' experiences of services and support in general, but also outline the needs of particular groups of carers in more detail when the responses were significant enough to make generalised conclusions. Specific issues in relation to BME carers are discussed in some depth as a priority area for the Scottish Executive.

The experiences of carers are discussed under the following themes, in line with the topic guide:

- Type of care experience
- Co-ordination of care services
- Specific issues in relation to BME carers
- Provision of information
- Effectiveness of policies to support carers
- Employer-based support for carers
- Education
- Carers' health: psychological and emotional support
- Contact with social workers
- Priorities for carers over the next 10 years.

3.2 Type of care experiences

The carers we spoke to had many different experiences of caring. Most cared for one or more immediate family members – such as partners or siblings – and some for other family members and friends. Some were sole carers, whilst others shared the task with a spouse or partner or other family members. Caring tasks included washing, dressing, feeding, lifting and assistance with medication, as well as general household chores, running the household, assistance with paperwork and shopping, emotional support and support for other family members. Some carers spent almost all their time caring and others had additional responsibilities, working part-time or full-time. Some carers cared for someone living in their house, whilst others travelled to take care of family members and/or friends. Respondents emphasised that caring was time-intensive and exhausting, and in many cases an isolating experience. Some had cared for a long time, whilst others had only recently set out on the journey of caring. For some, caring will be temporary, whilst for others it will be an inescapable reality for the foreseeable future.

The situations of carers are very different according to the circumstances of the people they care for. We spoke to carers who cared for people with multiple sclerosis, cerebral palsy, dementia, Alzheimer's, strokes, blindness, deafness, autism, mental health issues, severe mental and physical disability, multiple progressing illnesses, alcoholism, allergies, diabetes, serious accidents, and even those who have difficulty getting a diagnosis. In many cases, carers themselves suffered from poor health, and some referred to feelings of stress and depression.

The situations of carers also varied according to their age. Younger carers faced particular issues in terms of their own lack of social development, motivation and confidence. Many were uncertain about the future. Elderly carers had particular concerns about suitable housing and financial support.

Differences in experiences have a particular impact on how supported carers feel and their particular needs for the future. The experiences of carers could be approached from many angles. Whilst there are undoubtedly specific issues in relation to carers of specific ages, backgrounds and in particular caring circumstances, these issues are too detailed to account in a report of this nature.

It is evident, however, that those who care have little choice but to provide unpaid care for those they love, and simultaneously want to do as much as they can, at times to the detriment of their own health and safety. Some feel supported in their situations and others feel less so. From our conversations, it is clear that carers go through a journey in their experience of caring. For some, assuming a caring role has been sudden, whilst others have had more time to get accustomed to a situation where a condition progressed over time. Initially, carers are overwhelmed by their situation, and most in need of support, information and advice. As their situation 'matures', their support needs remain, but change, with most carers feeling more satisfied with the levels of support and services they receive:

'At the outset it was a real horror story. I did not know what was happening. There was no one to tell me what was happening. There was no one-stop shop. Everything came in bits and pieces. I am an engineer, a practical guy, but I needed a lot of practical help.' (Elderly man caring for his wife, suffering from Alzheimer's)

3.3 Co-ordination of care services

The carers we spoke to found themselves at different points along their caring journey, and therefore their experiences of the co-ordination of care services varied widely.

Some carers had contact only with a limited number of services and therefore had little experiences of the way care services were co-ordinated. Many elderly carers had contact only with a GP. In some cases, the GP acted as the channel to wider support for the carer, but this was not always the case. Elderly carers often perceived themselves as being burdensome if they asked for help from a social worker and/or other voluntary organisations. Many elderly carers also cared for elderly people who were suspicious of the help offered by social workers and others.

Caring, amongst elderly carers, was very much perceived as a duty; therefore, this group tended to rely less on services:

'I don't complain about it. It is what I promised to do 62 years ago when we got married. She's been caring for the children and me for over 60 years.' (Elderly carer caring for his wife suffering from dementia, Edinburgh)

'My wife is very resourceful. She is very independent. How she copes I do not know, but she does. She doesn't complain. No way would she complain. She is not unhappy doing it.' (Elderly man describing his elderly wife caring for a sister with dementia in a very demanding situation, Fife)

'I think people are penalised if they worked. I was brought up to be independent. We cared for ourselves. I never begrudged at any time looking after my mother. We took it as part of our life. I did not expect any rewards. It was only when I came to Nairn that I discovered a carers group. I said I am not a carer, I'm a wife! I am doing what is expected of me.' (Elderly carer, Nairn)

In general, many carers' **first point of contact** was with their **GP**. Most carers recognised that GPs play an important role in accessing a wider range of services. Whilst some were very satisfied with the support they received through their GP, others complained that not enough was being done by GPs to ensure that carers accessed a wider range of support services, such as a social worker, or even a counsellor, **early** in the caring process.

Carers who cared for people with **mental health problems** expressed some dissatisfaction with **GPs and psychiatric nurses**. The level of support was generally perceived as less than satisfactory, and carers often had to struggle to access wider support. GPs and psychiatric nurses were reported to fail in:

- recognising the seriousness of conditions;
- being empathetic towards the carer and the cared-for person;
- exploring different methods of treatment, with undue emphasis on taking medication; and
- sharing information, because of patient confidentiality.

Carers in these circumstances reported feeling powerless. These issues were also particularly prevalent amongst carers who themselves had mental health issues:

'My GP [whom is shared with her mother] is useless – he is very young and inexperienced and refused to get help for my mother and I don't think he realised the extent of her illness, and neither did my mother. Every time I tried to ask about her, it was like talking to a brick wall – he would just keep repeating that he couldn't disclose anything as it was confidential information.' (Carer with mental health problems, Glasgow)

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

'Going to the GP was a complete waste of time – even when (his wife) had a CPN I was never allowed any information because of the confidentiality issues – her life was seen as none of my business.... ' (Carer with mental health problems, Glasgow)

'At one point my mum was down to 5 stone, but the GP didn't seem to think it was that problematic and neither did my mum – every time I tried to get her a referral, I felt like no one was listening to me.' (Carer with mental health problems, Glasgow)

Other carers, in particular those in **need of specific equipment and alterations to their housing**, had many concerns with the way services were co-ordinated. They were shocked at the lack of co-ordination between, for example, occupational therapists and the service providers doing the alterations to houses and/or delivering equipment. We heard many stories of alterations made that were inappropriate and based on a complete lack of understanding of the needs of the disabled person, and therefore a waste of money, or equipment such as hoists that were not suitable for the size of the particular house or room. Furthermore, alternative housing suggested by housing departments was, on many occasions, unsuitable, even after an occupational therapist from the same local authority visited the family.

Many carers were concerned about the **changeover in support and services** when they moved from caring for a **child to caring for an adult**. Support for children was perceived as better than that for adults. Finding appropriate services and support was a very demanding process for carers, and often required a lot of mental energy:

'So far our story is good. At the moment services seem quite open towards children, but what happens to my boy when he is an adult?' (Woman caring for a disabled child, Dingwall)

'It is not easy. There are just not services out there for people like my son – even now. Younger parents have said how do you manage to get all of this for your son and I have said you have to keep on and on. I used to hate calling people and writing to people but eventually that is the only way.' (Woman caring for son with autism, Inverness)

There was a lack of co-ordination between services and support for the **cared for and the carer**. Many carers emphasised that it was essential to consider the **whole family** in a caring situation, and not only the person requiring the care:

'You can't disassociate the person you care for from the carer.' (Man caring for a partner with MS, Dingwall)

'Look at families. See how you can help the whole family. See how you can help to make the family normal again.' (Woman caring for her daughter who is severely mentally and physically disabled, Fife)

'My son's social worker is for him. There is nobody for me. It would be much better if the social worker took on the whole family.' (Mother of six children, including a son with autism, Easter Ross)

A number of participants caring for people who had both **caring and nursing needs** emphasised the lack of co-ordination in budgets between **the health service and social services**. Often carers cannot find the right type of respite care or day care, because of lack of nursing provision:

'There are fewer barriers on the health side of things than on the social work side. There is always a struggle of whose budget. Why can't they work closely together?'
(Carer of woman with Alzheimer's, Fife)

Voluntary support organisations played an important role in **co-ordinating services**. Many carers were assisted by carer organisations that played an important advocacy role on their behalf. This was particularly the case amongst carers suffering with mental health problems and learning difficulties, many of whom had difficulty articulating their needs. For example, we spoke to one deaf carer who had difficulty impressing upon her support team how serious her partner's drink problem was, and therefore felt unsupported in dealing with the rough and smooth of his mood swings and financial demands.

Most carers expressed the need for a particular individual to manage their whole situation, and co-ordinate all the service providers involved. Some saw this as the role of the GP; others thought it suited social workers better. This care co-ordinator could potentially play a key role in providing information about the suitability of services on offer, as well as being accountable for how carers were progressing and coping in their caring role.

3.4 Specific issues affecting black and minority ethnic carers

The issues set out elsewhere in this report also have salience within BME communities. The study did, however, identify a number of issues that were very specific to BME carers, and so for this group these are detailed below under the following headings, after a summary:

- Type of care experience
- Communication barriers to accessing care support services and information
- Institutional and cultural barriers to accessing care support services
- The need for future service provision to be tailored to the needs of BME carers.

Summary of specific issues in relation to BME carers

- In common with all carers in the study, BME participants had a variety of care experiences, involving washing, dressing, feeding and assistance with medication, as well as general household chores and running households.
- Caring responsibilities tended to cluster around conditions resulting from chronic heart disease and angina, as well as hypertension and diabetes, which confirms evidence from other UK studies about the higher propensity of people of African, African Caribbean and Asian origin to contract these conditions.
- A recurring theme within all the focus groups with BME carers, particularly among older carers, was the language, cultural, and institutional barriers that prevent or inhibit BME carers from accessing support services, either for themselves or for the person they are caring for.
- Care was seen as the responsibility of the family, making it difficult for BME carers to accept respite care.
- Conditions such as mental illness and dementia were seen as unmentionable in BME communities, and as something to be kept within the confines of the family, making it difficult to ask for outside help.

- From the perspective of some BME carers, the pressure on them to provide support was also related to expectations, stereotypes and myths on the part of the providers of statutory support services, particularly when they were dealing with Asian families.
- The younger participants, particularly within the Asian community, pointed to a shift in cultural expectations about care and the family, away from depending largely upon the family for care, towards increasingly having to accept care from statutory and voluntary providers.
- Eurocentric models of assessing care needs could act as a barrier to services within communities that are open to receiving them.
- Access to psychological support for BME carers was limited by lack of provision, and by negative cultural perceptions of stress and depression.
- Mainstream services were seen as needing to change fundamentally in the future, by acknowledging the existence of BME communities much more in the way they plan, promote and deliver their services.

Type of care experience

As with other groups in the study, BME carers had a variety of care experiences, involving washing, dressing, feeding and assistance with medication, as well as general household chores and running households. However, among Asian participants, there was some clustering of caring responsibilities around conditions resulting from chronic heart disease and angina, as well as hypertension and diabetes, which are also known risk factors for stroke. Indeed, the pattern in this study confirms evidence from other UK studies about the higher propensity of people of Asian origin to these conditions (see for example, Webster, 1997; Alexander, 1999; Puri, 2003)². This has obvious implications for access to culturally sensitive services.

The experiences of the following two participants typify the care experiences among Asian people who participated in the study:

'My mother-in-law has diabetes, she has angina, she's got blood pressure and she is on about 29 tablets a day. So, we have this medication box. She is not able to go to the toilet so we have a commode in her bedroom so that when she comes round we have to empty that. We get up at 6 o'clock in the morning, give her a cup of tea and give her some medication and then at 9 o'clock we have to give her something more solid to eat and make sure she has her medication. She can only walk with a walking frame so then you have to assist her to go to the toilet and then bring her back and get her changed and everything and encourage her to do her exercises because of her knee replacement.' (Woman sharing the caring for mother-in-law with other family members, Glasgow)

² Puri, Harsha, Bissell, Paul and Anderson, Claire (2003) Explanations for inequalities in health among people of South Asian origin living in the UK: the views of pharmacists, *International Journal of Pharmacy Practice*

Webster, R (1997) The experiences and health care needs of Asian coronary patients and their partners – methodological issues and preliminary findings, *Nursing Critical Care* 2 (5): 215-23

'My mother has diabetes. She doesn't really understand the cycle behind it to say that OK, what's going to happen to the food when it goes into the system and every time you eat something sweet or you eat something salty...I have to remind her sort of constantly, OK, this is what it's gonna do like, this is the amount of sugar it's got in it.' (Woman caring for her mother, Edinburgh)

Communication barriers

One of the recurring themes within all of the focus groups with BME carers, particularly among older carers, was the issue of language, and the way in which this prevented or inhibited some of them from accessing support services. The impact of this was felt acutely, in a number of ways. First, carers found it difficult or impossible to locate and understand information about available services; secondly, the person receiving the service might not be able to benefit because of language barriers; and thirdly, carers worried about the potential effect of receiving services on the person being cared for. A Chinese participant who shared the care of his son with cerebral palsy son jointly with his wife explained that, as someone who was effectively westernised and proficient in English, he was able to access services as needed, or was at least able to ask relevant questions. However, he articulated a view expressed by other BME participants about communities of carers being effectively denied services because the language of delivery was English. As he explained:

'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.' (Man caring for son with cerebral palsy, Edinburgh)

Similarly, an Asian participant who had been caring for her father-in-law described her reluctance to access support services that were made available to her, because of her concerns about the language barrier between those who provided the service and her father-in-law. She put it in this way:

'One of my friends, she keep saying you can get this one, you can get this one but I was so scared. I thought well, it's my father in law who didn't speak any English at all so no point to leave anybody with him. I was too scared because he can't speak the English. He might think, "Oh my God, she left me" so I have to stick with him all the time.' (Woman formerly caring for her father in law, Edinburgh)

As well as difficulties in accessing and taking up services, some participants described negative experiences resulting from services that were predicated on a Eurocentric model of delivery. As the services were not the correct *'fit'*, BME carers often had to take the initiative to supplement them in order to make them more responsive. The experience of a Chinese carer whose elderly mother was in residential care exemplifies this:

'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)

Language support was a significant issue; however, some participants, particularly the younger ones, felt that over a longer time period existing barriers resulting from a lack of language provision might become less of an issue, as the needs of the second and third generation came into play, particularly with curtailments on immigration. However, the need to plan for appropriate services, which recognise the culture and faith of BME communities, was seen as an issue that would be important throughout successive generations.

Institutional and cultural barriers

The study identified a number of institutional and cultural barriers that prevented BME carers either from accessing support services or from being satisfied with the services that were being provided.

Access to support services

Whilst participants in the overall study welcomed the provision of respite care, the majority of BME participants felt that caring was the responsibility of the family. As such, sending a relative away for an extended period to provide the carer with a break was completely taboo, as it went against cultural and family expectations. Moreover, BME participants pointed out that taking advantage of respite care would be humiliating for the carer and for their families, since it would give the impression to the wider community that they were unable to cope. The study also revealed that conditions such as mental illness and dementia were seen as *unmentionable* in BME communities, and as something to be kept within the confines of the family. This made it difficult to ask for outside help.

'It's like sending the dog to the kennel for a week or so.' (Woman formerly caring for her father-in-law, Edinburgh)

'I think that sometimes ethnic minority people may be ashamed to ask for help for them to look after the family members and they think that it is not right for them to ask for outside help. They don't know how to do it or they think people will think they can't manage.' (Woman caring for her father-in-law, Glasgow)

'It's a big thing in the ethnic minority you know that you have to look after your own family and that if you don't it's like degrading' (Woman caring for her mother, Glasgow)

Some BME carers, however, also felt pressures upon them to provide care due to expectations, stereotypes and myths on the part of the providers of statutory support services, particularly when dealing with Asian families. Indeed, Asian families were seen to be part of an extensive family network and there was therefore an underlying assumption that they should or could provide all of the necessary support to the person they were caring for. An Asian participant who cared for her husband's grandmother recounted her experiences:

'... she needed 24 hour care and somebody to watch over her during the night and when we applied for it, it took them 5 weeks to put into place and on the sixth week she was dead. They didn't have a clue. It was terrible, terrible.... They should have been able to understand. They just looked at the extended family and thought, 'there are all these people here'. The assessment was all wrong.' (Woman caring for her mother-in law, Glasgow)

Shifting cultural expectations

The younger participants within the Asian community did, however, point out that expectations were shifting, albeit slowly, and that using support services was seen by the younger generation as less of a stigma, and as more of a right.

'My Mum would say, "my God, what the hell is wrong with you. You can't look after me." Our generation though they say "OK, something's available, why not use it?" Because that's the reason why they've been set up out there because there's a need for these things, but the thing is for the older generation, approaching it sends different signals for them.' (Young woman caring for her mother with disabilities, Edinburgh)

Eurocentric models of care

Participants who were more open to the notion of respite care or other support services for carers were concerned that they were predicated on a white European model of a person's care needs, which made them inappropriate. The two following examples illustrate how the provision of services or formalised assessments of personal care needs can act as a barrier to services:

'If they want to pray, they want to be able to do their ablutions properly, you know, because even though some of them might not be able to kneel and pray, they can still sit on the chair and do it and they would want to keep up with that. Also we would be worried about their culture and their food and whether it's Halal so you have to take everything into account.' (Woman caring for father, Glasgow)

'In Western culture, a person either takes a bath or takes a shower and so the model of assessment is based on that. However, in the Chinese community, elderly people do not take a bath or a shower, but climb into the bath tub and make use of a bucket of water and splash themselves and of course, the Occupational Therapist cannot fit this into their set of rules.' (MECOPP Focus Group Interpreter, Edinburgh)

Access to psychological support for carers

The majority of participants in the BME focus groups were the sole providers of care, and they were mostly women. However, a limited number of participants did share the responsibility for the personal care of a relative with another family member. Most participants described the stress and depression resulting from the demands of caring, as well as the loneliness and isolation. Despite the myths participants identified on the part of statutory providers about support networks within Asian extended families, a significant number did not have an extended family to fall back on. Family members either did not live close by, or more often, were pursuing their own lives. The impact of having to take prime responsibility for caring therefore took its toll, as the following example illustrates vividly:

'I find at times a person can get down, and we get down as well but we've got to, just stomp ahead 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 and 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)

It was in these circumstances that participants identified the need for psychological support. However, as well as being afraid to ask for help, carers felt that within the Asian community there was a stigma attached to needing psychological support. In any event, participants were unaware of what was available or where to go for help. Fears about accessing psychological support services and the associated stigma were directly linked to cultural expectations about the family as the provider of care services, and the way in which being seen as unable to cope would impact adversely on the good name of their families. A persistent theme among participants also related to concerns that outside agencies might not treat their issues as confidential, particularly where the service was provided by another Asian, and that approaches for help would get back to the person being cared for and to the wider community. The views of the following three participants illustrate this:

'I think again that it is a cultural restraint. I mean if I knew there was another Asian, call me paranoid or what. For example if I went to someone and confided and said "Oh I'm a bit tired" or whatever that person, I assume would automatically assume that she can't be bothered looking after her mother anymore and that would be a black mark against your name or your family name and that is part of the stress as well because you cannot offload onto anyone, especially of course with them being Asian. You've always got this constant fear in your head about what they are going to think... If they were there and if I knew they would be definitely confidential and they had that cultural respect then maybe I would not be so paranoid, but because they don't provide it in the first place and having a bad experience with social services, I don't think they respect carers enough.' (Woman caring for mother, Glasgow)

'I mean I suffered from severe depression and that and I found that in the Asian community, you are just supposed to get on with it. Even if you have a mental illness you are supposed to just get on with it. You feel embarrassed and worry about anybody knowing about it as well because you thought people from the Asian community if they found out about it, what would they think.' (Woman caring for father, Glasgow)

'I think if they know they could come in confidence and ask, and first letting them know that there is help available. Like in the sense that if that person needs help but he doesn't want the other family members to know I need a wee bit of help or I need someone to listen to me and he doesn't want anybody else to know that he's not coping so well, you know and he needs time out. Knowing he can go in confidence and talk to someone and nobody has to know about it.' (Woman caring for father, Glasgow)

Future service provision

The changing role of women, particularly in the Asian community, as a result of them becoming more educated and focused on a career rather than early marriage, will have an adverse impact on the availability of care within the family. Thus participants saw the community as being in a process of transformation, from depending largely on the family for care services to increasingly having to accept care from outside agencies. Moreover, patterns of change among the younger generation more generally are leading to the possibility of families becoming more fragmented, resulting in an even more limited pool of carers. As one participant explained:

'They (the younger generation) want to pick and choose. So, if it suits them, they will choose to keep it. If something's not working, they'll say 'Oh, I can't do it' automatically, and just walk away from it.' (Younger woman caring for a mother with diabetes, Edinburgh)

BME carers saw mainstream services as needing to change fundamentally in the future, by acknowledging the existence of BME communities not only in the way that they *delivered* their services, but in how they *planned* and *promoted* them. In practical terms, this might translate in providing more secure funding for the voluntary sector to assist BME communities in accessing care services, and in providing more bilingual workers to run statutory and voluntary services, thus making dialogue with families easier. Participants emphasised the need for mainstream provision that takes full account of BME communities, ensuring that they receive a more effective service, rather than separate provision tacked onto mainstream services as an afterthought. One participant explained it in this way:

'...mainstream and keeping it all equal but acknowledging I guess the ethnic minority a bit more and to know that they are hesitant and they are probably a bit embarrassed to approach them.' (Woman caring for her mother, Glasgow)

Participants were concerned that, if services did not change in the future, their prospects would be bleak, and their caring role relentless:

'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)

'Hard to say, if like I've got help, and like I say, if help is available and there is help for me then fine. If not, it does look bleak then I would say because it's pretty hard. It's not easy looking after someone, you know. I wouldn't, you know, put her in a home. I would look after her if I could for as long as I could.' (Woman caring for mother, Glasgow)

The respondents saw language barriers as something that might change through the generations. Nevertheless, they emphasised the continued need to plan for culturally appropriate services, sensitive to culture and faith. This research exercise illustrated the need for culturally sensitive services to be backed up by action in the form of more effective information provision within the Asian community. Information should be provided in community languages in accessible places, such as community centres, doctor's surgeries, mosques and adverts in the ethnic press or radio.

3.5 Information

Opinions amongst carers about the provision of information varied widely. No particular conclusions can be drawn that relate to a particular age group of carers or carers in any particular caring situation. Carers in contact with carers' support centres felt well informed. The research, however, brought out a number of issues in relation to information, which it is important to take into account in looking at future support for carers.

Information on services and benefits

Carers cannot access information from any **central point**. Most carers we spoke to discovered relevant information by chance or through word-of-mouth. Many suggested that GP surgeries would be a good point for providing information. Some carers even suggested that providing information to people who find themselves in a care situation should be mandatory. More often than not, information is focused on the cared-for person and not the carer:

'...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 was particularly difficult to access information in rural areas:

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

Carers found it difficult to get information on the benefits they were entitled to, such as the Carers' Allowance, council tax reductions and Disability Living Allowance. In most cases, they felt that they were seen not as people in need but as another possible expense, and therefore those providing information were not forthcoming. Many carers who opted for Direct Payments felt that obstacles were put in their way:

'It's a kerfuffle. It is means tested, which annoys me. If somebody has cancer no questions are asked about the amount of care provided to them. If it is Alzheimer's or dementia it is just – you've got money and we want it.' (Carer of woman with Alzheimer's, Kirkcaldy)

'Sometimes they don't see people; they just see how much it will cost.' (Carer, Edinburgh)

Many carers, in particular young carers, felt that **medical and other support staff** did not always **explain terms or situations** clearly enough to them. They felt the more they understood the condition(s) of the people being cared for, the more they would be able to deal with the situation.

Wider understanding

Many carers felt there was a need for wider society to be educated on unpaid carers, including in local schools. Young people with normal circumstances at home often had little

understanding of the plight of young carers. The need for the education of society on caring was also emphasised by many other carers. One carer illustrated this well:

'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)

Two-way communication

Many carers emphasised the need for an **effective two-way communication process** between carer and service providers, such as social services and health services. Often the carer is not recognised as an equal expert on the person cared for, or involved in decisions. This lack of involvement as a partner in caring is a source of great discontent amongst carers, young and old:

'They don't involve you as a young carer.' (Young carer on social workers, Isle of Skye)

'I know my mum inside out. I know when she is hyper. When you are trying to explain the situation to people they think you are making it up. They are just seeing it with tunnel vision. They don't pick up what is going on with my mother. That's what you are up against all the time – someone telling you she is all right.' (Daughter caring for a woman with mental illness, Fife)

'They should involve us in assessments because if anything changes in our family it affects all of us. They never involve us.' (Young carer on services working together, Isle of Skye)

3.6 Effectiveness of policies to support carers

Most of the carers we spoke to felt that not enough was being done by the Scottish Executive to support and recognise carers. Moreover, they felt that, although more money was made available to carers, it was difficult to access these resources. Carers felt they were treated with suspicion by the system; and were continuously tested through endless bureaucratic hoops, being required to fill in complicated and repetitive forms:

'I get frustrated with the bureaucracy, the rules and the regulations. You have to justify yourself all the time.' (Carer, Edinburgh)

'You need a Philadelphia lawyer to fill in the forms. The forms could be simplified.' (Husband of woman with Alzheimer's, Fife)

'It is almost like the government don't trust us. Sometimes I think they just care about the person with the disability. They don't think about the whole family. They should think of the family around the person with the disability.' (Carer, Edinburgh)

'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)

'People are terrified of losing their benefits – when you are filling out the forms, you can put one word wrong and lose the lot. The amount you get given is chosen by someone who knows nothing about your physical condition – if a doctor says you are ill, that should be enough. We shouldn't be forced to do degrading things like climbing stairs and having people poke and prod you to check you aren't a fake.' (Carer with mental health problems, Tullibody)

Carers had different perceptions of the effectiveness of policies to support carers, depending on their age. Elderly carers felt there was little consideration for their plight, in particular once they achieved pensioner status. Many elderly carers experienced financial hardship, because of the extra cost imposed on them because of their caring role, and the fact that they did not qualify for a Carers' Allowance when receiving a pension of greater value. Some elderly carers felt they were penalised by the system:

'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 Carers' 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)

'The government is ageist. Life according to the government stops at 60. There is no outlook to older people. I've lived in Germany and the way they treat their elderly people is so much superior. It is not fair.' (Elderly carer, caring for a husband and an aunt, Edinburgh)

Elderly carers also felt that, although it was part of the government's policy to keep people in their own homes as long as possible, there was a real need for suitable sheltered housing for elderly people caring and being cared for. This was particularly prevalent in rural areas.

Many young carers felt more should be done to create support organisations and respite breaks for young carers, to give them a chance to take a break from their caring responsibilities, and to have the necessary emotional support to make them feel more confident socially. Those young carers who had access to young carers' groups felt very supported by them, and valued the informal atmosphere and non-threatening environment to talk to the workers at these groups:

'Without the Project I would be dead; it links between home and school and others to help explain things. It's not just about workers caring but helping with my education

and health. The breaks are useful; the only time I get out. They can also get in touch with others who can help me.' (Young carer on the value of the young carers' project, Isle of Skye)

Many carers had grave concerns about their financial future, in particular when they had been a sole care provider and had been caring for a number of years, and were therefore less able to seek full-time employment. They felt the government was not very supportive in recognising their contribution and therefore ensuring financial security for them once they reached retirement age. Furthermore, the ceiling placed on part-time work when in receipt of a Carers' Allowance also limited carers' quality of life. This was felt even more intensely in cases where care was provided to more than one person, or to friends:

'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)

'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 Carer's 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)

'I have no pension. I've never had any money to put in a pension. If anything was to happen to my son, I am left with nothing.' (Sole carer of adult son with autism, Edinburgh)

'Sometimes I feel like I don't want to be a carer anymore...carers are penalised financially and its not fair.' (Carer with mental health problems, Glasgow)

There is no incentive to provide adequate training to carers to fulfil their role. Many carers talked about the fact that they had received no formal training to lift, bathe and help move around the people they care for.

'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)

'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, Western Ross)

Carers felt that their health and safety was unimportant to the government. A large number felt that the health and safety regulations home care staff are subject to makes them a less useful service, and does not take into account unpaid carers' health and safety:

'I am all in favour of someone not putting themselves at risk in their workplace as much as possible. The realities are if you are looking after someone with a disability who is immobile you are going to need to be able to bend over and move about. We are talking about home care. Home care have taken on board so much health and safety that they are actually safetying themselves out of home care.' (Carer, Fife)

'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)

Suitable and adequate respite care provision continues to be an issue amongst carers, particularly in rural areas. Carers felt it was important to be able to place trust in the respite care provided. A number of carers mentioned that respite is often withdrawn at the last minute, with little explanation. Provision for longer respite breaks are often not tailored around groups that require specific types of provision, such as younger adults with nursing and care needs. Many carers continue to depend on family members for the provision of respite care.

Carers in rural areas felt that little attention was given to accessibility of services, such as transport. In some rural areas, such as Eastern Ross, some have started innovative schemes such as an informal taxi service, run by the local community, which is more affordable than a formal taxi service and more regular than public transport.

'Access on buses for the disabled is non-existent. North of Inverness there are no accessible buses.' (Carer, Easter Ross)

People caring for those suffering from less 'visible' conditions felt very unsupported by the system. They emphasised the reluctance of health and social services to provide support for those suffering from mental health problems and alcoholism, particularly in rural areas, and also to support and recognise carers in their role.

'Because my brother is an alcoholic people won't care. Alcoholism is an illness. If he had any other problem they would have helped him. No one takes it seriously. It is hard to see someone you love destroy themselves.' (Woman caring for her brother with alcoholism and mother with mental illness, Fife)

'I am thousands of pounds in debt. There was nothing in the services. They never mentioned any support. I am not getting any help other than what I pay for. They (the GPs) just walked away. They are not answerable to anybody.' (Carer of son with mental health problems, Easter Ross)

Carers suffering from mental health problems and learning difficulties also talked about being stigmatised by society, particularly in smaller towns and rural areas. Some carers in these groups were prepared to be more open about their condition than others.

'The stigma attached to mental health problems means people just don't know how to deal with it. I feel like my whole life is encompassed by my caring responsibilities. I just want to be treated normally.. (Carer with mental health problems, Glasgow)

'The stigma attached to mental health must be removed. Because my wife and I are so open about our conditions, people know that they can come to us for advice and help whenever they need to, but lots of people don't have that support.' (Carers with mental health problems, Glasgow)

One carer with mental health problems felt things were slowly changing for the better:

'I have seen lots of changes occur within the last 18 months following the advertising campaigns about mental health – and people seem pleased that they are finally able to talk about their issues, but a lot more needs to be done. Information about mental health issues is much more accessible.' (Carer with mental health problems, Glasgow)

Carers were unanimous that very little was done to assist them in practical ways, from practical help around the house, such as cleaning, changing bulbs, and so forth, to other ways, such as blue badges for parking and assistance with fuel and heating costs.

'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)

3.7 Employer-based support

The vast majority of participants in the study were women and they were concentrated almost exclusively within part-time work, and in particular in the traditionally low-paid occupations in which women tend to be over-represented. Their occupations included child minding and other formal care roles, sales assistants, sessional youth work and community work that allowed participants flexibility on a day-to-day basis. In this sense, employment and career trajectories were often shaped by caring responsibilities, or decisions were made by carers to stay in a particular job because the organisation of work fitted into the rhythms of the caring and family life. The following examples illustrate this:

'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)

'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 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)

Indeed, some participants had focused on their career and training needs specifically as a result of their caring. The following example of an interviewee who was currently training to be a counsellor illustrates this:

'The hours were a major contribution because when my son comes home, I've got to be there and if I'm not, there's a change of his routine and it would cause him stress, kicking, screaming....But in the long run the decision that I can work part time and when he's at school was the main factor. There's no point me saying I'm going to get a full time job in an office or even a part time job in an office because it just wouldn't suit the holidays and things like that, so in the long run it has made me sit down and think what I want to do career wise.' (Trainee counsellor, caring for her son, North Ayrshire)

Male participants who shared the caring responsibility with their partners tended to work full time. However, where they had sole responsibility, as in the following case of a man who had sole care for his two disabled children, balancing full time work and care was impossible. Moreover, the cost of childminders actually cancelled out the financial advantage of working:

'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)

Only a minority of employers in the study seemed to be supportive of carers, and most of this support was informal, on the basis of goodwill, where the employee was either a friend of the employer, or where a good working relationship had developed over a number of years:

'My employers are very understanding because there was an incident a couple of weeks ago. My daughter had just had enough and when I went in the morning, she put her coat on and walked out. I didn't know where she was. I've been there for 20 years. I volunteered for a long time first and I am now a paid worker. I encourage people in the community to eat healthy.' (Woman caring for daughter and grandson, Glasgow)

There were two examples of larger employers providing flexible work opportunities for carers: one was a leading bank, and the other was the Post Office:

'They were very good with me. If I needed time away for appointments they were very good.' (Bank cashier, caring for her mother, Glasgow)

'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)

It is, however, unclear whether this was part of a deliberate policy towards carers, or part and parcel of normal flexible working arrangements. A number of other carers also emphasised that they enjoyed working, because it allowed them to be themselves and provided an essential outlet to allow them to carry the emotional burden of caring:

'For my own mental well-being and ability to look after him, I need to continue to work. A lot of what happens with my husband is what I call one-way traffic. Through no fault of his own, he is not able to hold a conversation or do a lot of things. If I don't have something else in my life I would be in the local mental health hospital. I could not do what I do for him unless I worked.' (Carer, Fife)

Carers with mental health problems and learning difficulties emphasised that working was an important tool to make them feel valued and empowered. However, a small number of participants experienced difficulty in accessing employment:

'The careers centre is not doing enough to help him...he needs help to boost his confidence which will help him go out and get a job. He is too embarrassed to go and ask for help. He has problems with literacy but will not ask for support. He sees support as stigmatised and will not accept help.' (Carer with mental health problems, Glasgow)

3.8 Education

Education is an issue exclusively for young carers in the study. Young carers talked at length about the disruption to their education as a result of having taken on the sole (or sometimes shared) responsibility for the care of other siblings, a parent or a relative. The impact of caring manifested itself in a number of ways, including prolonged absences from school in order to fulfil care functions, the inability to develop close relationships with school peers because of caring commitments and embarrassment, and the inability to focus on schoolwork because of preoccupation with problems at home. The following young carers described the impact of caring on their education in the following way:

'I found it hard to concentrate. I was worried about going home and stuff, but now it's all right because I'm away from that. She was always drunk and that and sometimes I would go home and have to do the cleaning up because the house would be in a mess and that and I would have to clean it up. It's better now. When it came to tests and stuff, I wasn't doing it right because I didn't know what I was doing.' (12 year old girl with alcoholic mother, Irvine)

'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 who has cared for his mother since he was a teenager, Edinburgh)

'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)

Most young carers felt that schools supported them in their situation, when they were informed about it. However, they emphasised that a lot more could be done to educate schools and other children on young carers. They felt it was very important for schools to treat their situation confidentially:

'It's sort of hard because I have to keep missing school to take care of her but the teachers are all helpful and send work home for me. I've missed it every day this week because my Mum, she's been stuck in her bed. I had to take her to the toilet and help her in her chair and that and help her about the house and stuff.' (15 year-old girl, caring for mother with arthritis, Irvine)

Young carers often had low expectations about their abilities and prospects for the future. They felt responsible for continuing to provide care, and worried about the continued wellbeing of their family members, which might impact on their own education. Many young carers felt that additional support and motivation were essential to young carers:

'They feel there is nothing for them; that they will end up in a dead end job. I feel like that sometimes. I feel there is not going to be anybody out there.' (Young carer on other young carers, Fife)

'I'd like to go away for a while and then return home. I'd like to do something around art. At home I'd need to know that things are safe and that dad is more stable. I don't think anyone else can do this and I'm not sure if dad will accept support from anyone else.' (Young carer, Isle of Skye)

3.9 Carers' health: psychological and emotional support

Caring is demanding, and carers are unanimous in expressing feelings of exhaustion, stress and isolation. Caring implies a lack of freedom and very little time for self. Often, former friends disappear, and carers are left struggling with a range of professionals, sometimes with the support of other family members, and at times alone.

A common concern expressed by carers was the lack of support to help them with the psychological and emotional demands of caring, as they were often isolated and depressed. They often felt that they could not express their emotions to the professionals they dealt with, out of fear that they would be seen as unable to provide care:

'It doesn't matter how well you get on with professionals. You can't say anything to them. You will be immediately branded as an unfit parent. It is such a relief to talk to somebody else who won't judge you. I hate those books about wonderful parents who never had anything in their life, whose caring experience supposedly changed their life so much for the better. I wish sometimes people could be more honest because there had been days I could have screamed.' (Carer, Inverness)

Carers with mental health problems and learning difficulties in particular reported strong feelings of isolation, frustration and disempowerment because of general lack of understanding amongst the public, services and family and friends of their complex needs:

'He doesn't understand the concept of me being ill which makes it very difficult to have time off from caring. I am so tired all the time – caring has had a real effect on me. I lose patience with him and I don't want to – I just can't help it though.' (Carer with mental health problems, Glasgow)

'I have nowhere to turn ... I want someone with some insight into what I'm going through – someone who understands mental health issues.' (Carer with mental health problems, Glasgow)

The lack of counselling services as well as lack of knowledge of counselling services was a common experience among most adult carers, whether they were caring for elderly people or young children. External support and information about counselling services is not widely available, although the carers who had accessed such services experienced relief:

'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)

'There should be family counselling for people that have people with disabilities. They shouldn't have to look for it; it should be given to them. A caring role is enough. We shouldn't have to go to Tom, Dick and Harry to see what's available. One of the golden rules should be counselling. We could do with counselling for the whole family...there are many issues bogging you but where do you go? You just have to grin and bear it and get on with it.' (Woman looking after her husband, North Ayrshire)

The lack of emotional support services for carers was also seen as linked to the *invisibility* of carers: the tendency to focus services on the person being cared for, leaving carers out of the equation. The Princess Royal Trust and other carer support centres in the charity and voluntary sector were seen as key in providing much needed support, in particular through carers' groups:

'Without the carers group and without that support, I would have found it very difficult. I wouldn't say I used the social services any more than was necessary. This was more support to me, I have to say, than social services, until the stage I am at now where he has to go into full time care and they have been very supportive; but before that, they didn't offer me a support group like this where you could go and talk to people and things like that. This gives me time to talk about it and listen to other people.' (Woman caring for her husband, now in residential care, North Ayrshire)

'Because you can get out of the house, you can meet other people and we don't tend to dwell on our problems but there is somebody there that will understand if you have a problem and will know where you're coming from. We cheer each other up. A therapist usually comes so we'll get a therapy session which is very relaxing, aromatherapy or a

massage which is very relaxing so that it gives you a big boost.' (Woman caring for her daughter, North Ayrshire)

'The support group is excellent and probably my biggest source of support. I can discuss my experiences with other carers who understand my situation. The only drawback is I cannot always make the support group because of my caring responsibilities.' (Carer with mental health problems, Glasgow)

Often the lack of provision meant that carers had to establish their own psychological support mechanisms, thus responding to an identified need that was not being addressed by providers of statutory or voluntary services, particularly in rural isolated areas:

'I mean we have set up our own support group on the Island now because we found that there wasn't anywhere. It was through going swimming and all the children with disabilities being put in a swimming class together and we just sort of got talking and we found that there was nowhere for us to meet and discuss our different problems. There's no sort of drop in centre like there is on the mainland. It's been going for almost a year and we've been trying to organise activities for the children. We have applied for a grant, Lottery money. So, we got that. Some of the parents live on the other side of the Island, very remote so it's good for them to have that link and to get together with other parents. As individuals, no one would have known we existed.' (Carer, Isle of Arran)

'We are quite fortunate that in the last 6 months or so there's been a support group set up in Tain. They realised there was a huge need for a support group for parents of children with lots of problems and who don't necessarily have a diagnosis. That's been very helpful. Because my son is in mainstream education, if you go to other autism groups, you kind of feel really bad if you are complaining about your child because these parents have far more handicapped children. At Tain, our children attend mainstream school. We all totally understand that the fact they attend mainstream school has a whole set of different problems. It turned into the sort of group where we can all be really honest with one another. It has been a lifeline.' (Carer, Easter Ross)

Carers with mental health problems and learning difficulties, discussing the services that support them, mentioned the role and the importance of 'befrienders' a number of times. The befriending gave the person who was being cared for an opportunity to have some social interaction, as well as giving the carer a chance to take a break, as the following participant explained:

'(Her husband) used to have a "befriender" who would take him out once or twice a week. This used to be good, but then the standard of "befrienders" dropped. One man was not very nice to him so I stopped him from coming around, when I tried to rearrange with other people, the new "befrienders" just cancelled....now I don't receive any help at all.' (Carer with mental health problems, Glasgow)

Aside from lack of provision, another common issue was the lack of clear signposting to services, and the lack of co-ordination between statutory agencies and voluntary agencies providing counselling and support services. This is because no single agency is held accountable for the well being of carers:

'I think the very first thing is letting people know that they are carers and letting them know that they are entitled to support for themselves. That doesn't happen very much on the health side of things. Unless you have a really on the ball, like-minded GP, they just don't think about it. Part of it is the consultancy time – seven and a half minutes – and they don't want to breach it. Nurses are a little bit better, but we know that there are carers out there that don't know about voluntary support services.' (Carer, Fife)

Although support services did exist for some for young carers in both urban and rural areas, these were limited and constrained by lack of resources. Furthermore, provision for young carers from black and minority ethnic groups is entirely absent. The sensitivity of support services to the needs of young BME carers and how this meshes with cultural traditions is brought out in the contrast between the following experiences of white and BME young carers:

'We just go and have fun... We went to a few amusement parks and we go swimming just to get our minds of what is going on around us.' (White young Carer, Ayrshire)

'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)

3.10 Contact with care professionals

The researchers were asked to explore the roles and responsibilities of social workers in particular, so that the findings could be fed into a parallel national review of social work services. Consequently, most of the comments made by carers here relate to social workers, and not therefore to other care professionals such as GPs, statutory community or acute health workers, or staff from community and voluntary sector organisations. This is not intended to single out social workers relative to other professional care workers as the target of carers general dissatisfaction with statutory services. That is, views about other care professionals were not explicitly sought as a focus of this research, and so no comparison is made here.

The level of contact with social workers varied. It seemed to carers that social work departments had **no standardised system** across different local authorities in dealing with the needs of carers. General references to social workers, more often than not, were negative:

'They are shit. They didn't give us rights, lied to us, didn't give information or help when we asked for it. Me and my mum have been left traumatised by it.' (Young carer, Isle of Skye)

'If these people could see what we go through.' (Carer, the Highlands)

'You are told there are people worse off than yourselves.' (Carer, the Highlands)

'People who work in this area are either caring or controlling – my daughter's social worker is one of the controlling types – she doesn't really listen to us....All the assistance I have received with him I have got off my own back.' (Carer with mental health problems, Glasgow)

For many carers, particularly elderly carers or those caring for elderly people, resorting to a social worker had implications in being seen as a 'problem family'.

'People of that generation; they don't want social workers to gossip about them.' (Woman caring for her grandmother, Dunfermline)

Social workers are seen as overworked, untrustworthy, unprofessional and lacking in knowledge and empathy of carers' situations.

'There's far too much social work back stabbing. Far too much. I've been stuck in the middle various times to the extent that I complained to the Head of Social Work about it. I had my social worker complaining about the support manager, running him down, and other professionals were complaining about my social worker. They are just not very professional.' (Carer, Western Ross)

There was also a strong perception that social workers were not dependable and understaffed. The following two respondents illustrate this:

'They are supposed to turn up but very seldom do I get a social worker. The social worker had been on maternity leave but they are very short staffed in that office, so there's nobody really to step in. They struggle to get you somebody to start off with....Most of my information has come from the Carers' Centre.' (Carer, Ayrshire)

'I didn't feel they helped me at all because basically, my son's school has been great and it was them that got me, because he's on a special needs register. They said "Oh, you'll get a visit and the social work department will come down and meet you, tell you all the things that are available". The person that came down actually couldn't help me at all. He said "once your son reaches 18, there's a lot of things and a lot of information I could give you" - that was when he was 15. Nothing. It's like you hit a brick wall.' (Mother caring for her son, Glasgow)

Only a very small number of carers had positive experiences with social workers and were thus able to build positive, long-term relationships (an aspiration expressed by many carers). Staff turnover had a negative effect on the ability to form these relationships. In cases where social workers were perceived as caring, understanding and empathetic, it was evident that they were felt to have the power to make a lot of difference to the quality of life of the carer.

Carers had particular problems with Carers' Assessments, which were perceived as not working, offering empty promises. The following response is typical:

'Carer assessments – you fill them out and send them to social work. Diddly squat 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)

Carers emphasised information when talking about the type of service they wished to receive from social workers,. Social workers could be good sources of information on services, welfare benefits and practical support for carers. While this was seen as important in urban areas, the need for social work support took on an even greater significance in rural isolated areas where services were perceived as 'few and far between'. As an interviewee who cared for her autistic son explained:

'Everything is isolated and I think if you had a social worker you could access more services because what they say is, what you don't know you don't know sort of thing so they sometimes put everything together and get you the help that you need.'
(Woman caring for her son, Isle of Arran)

3.11 Priorities for carers over the next 10 years

Most carers found it difficult to think about the future, first because they felt that the current level of support was not satisfactory, and secondly because thinking about the future was daunting – that many carers feared for their own health, and therefore their continued ability to provide care.

Within this context, carers expressed the view that the concerns and difficulties they had currently would multiply and become more acute as they became older. However, they identified a number of priorities for enhancing access to support services, as well as the delivery of support services. These are set out below, not in any order of priority:

1. *Recognition of carers*

The role of carers should be properly recognised. For some this means caring being regarded as an occupation and supported accordingly by the Government, both financially and other support. Others expected the same rights and access to support that paid care staff receive, such as free health checks, inoculations, health and safety training. Carers expected to be treated as equal partners in the caring situation.

2. *Transformation of care models and mainstreaming*

Mainstream support services need to ensure equality of service provision and the cultural appropriateness of provision by making BME communities central to the planning, promotion and delivery of care support services.

3. *Funding for voluntary and community organisations*

Carers saw a need for voluntary agencies to have more secure funding to enable them to continue playing an important advocacy role on behalf of carers, thus helping carers to identify and access services, as well as to provide essential emotional and practical support.

4. *Care breaks and other support services*

Access to respite and short breaks, and the quality of these services when accessed was perceived by most to be very poor. More support needs to be made available to assist carers in the next ten years, including care breaks, outings for the people they care for, and assistance in the home customised to the needs of the whole family rather than determined by statutory agencies. Respite care should make provision for people of different ages and with different conditions.

5. *Future planning for carers of children*

More effective forward planning for the care needs of children with disabilities is needed, so that parents know what will become available from the outset, rather than being faced with a situation where there is nothing in place to enable them to cope with the transition from caring for a child to caring for a young adult.

6. *Targeting of information*

Information needs to be targeted more effectively at all groups of carers and the wider public, through schools, community centres, doctors' surgeries, churches, mosques, local radio and the ethnic press; in various community languages; and through better co-ordination between carers' organisations and statutory and voluntary agencies.

7. *Counselling*

Carers need more counselling services, on an individual basis or as families, to help children as well as parents cope with the demands of caring.

8. *Benefit entitlements*

Carers experienced the benefits system as complicated. Bureaucratic obstacles to carers claiming financial assistance need to be removed, and carers need more assistance with form filling and transparent advice on benefit entitlements.

9. *Bilingual workers*

Services should employ more bilingual workers, to provide the necessary support to BME communities, either in their own homes or in community-based establishments.

10. *Support for elderly carers*

Elderly carers need more support in the home to enable them to continue in their caring role if their own health deteriorates, to prevent the person they are caring for from having to go into a residential establishment.

11. *Support for young carers*

Young carers need more support and motivation, in the form of informal breaks and carers' projects and wider recognition of their contribution.

12. *Support for carers with mental health problems and learning difficulties*

Carers with complex needs need more support to help them access services in a fair way. There is also a need to continue to target the prejudices of the rest of society and perceptions of mental health problems.

13. *Assistance with fuel bills and other practical support for carers*

All carers, not just the elderly, need assistance with fuel bills and other practical support, since caring often means being in the home all day with the person being cared for.

14. *Island and rural carers*

Carers who do not live on the mainland or who live in rural areas need more support services.

15. *Consultation and partnership with carers*

Consultation should take place with carers who are actually doing the work, not carers' organisations, because a limited number of carers actually engage with these organisations due to a lack of knowledge.

Annex A: Topic guide used for BME carers, young carers, elderly carers, and carers in paid employment

Scottish Executive Generic Topic Guide for Focus Groups

Part One - Introduction (15 Minutes)

The facilitators to introduce themselves and explain that they are from OPM, a not-for-profit organisation that specialises in work with the public sector and which aims to improve the way public services are developed and managed to ensure better social results. Explain that a large part of our work that we do involves listening to the views of service users and the public in order find out their views and to inform the improvement of services.

Explain that Scottish Executive has asked OPM to undertake this project and consult with carers and carers organisations on the future needs of carers and how services might need to change over the next 10 years to meet their diverse needs. Explain that as well as working with carers, the project also involves soliciting the views of voluntary and statutory organisations that are involved in providing services for carers and those who are cared for. In addition, explain that the Scottish Executive is interested in the experience of BME carers and that this is an integral part of the project as well as a core component of the National Care Strategy.

Explain what we have found so far from the literature review and the survey about the kind of issues that have emerged and the kind of support informal carers see as a priority and the concerns about the longer term (These to be mapped on a flip chart as prompts for Part One of the Focus Group Discussion, e.g. co-ordination of care services; availability of support; the provision of information; the effectiveness of policies to support carers, e.g. respite care, flexible working policies – see below). Then go on to explain why we are here in relation to the issues that have emerged and the objective of the Focus Group exercise which is to elicit views on different aspects of services for carers looking principally at:

- What in your experience works well
- What in your experience does not work well
- **What in your view needs to be improved and how**
- **Identifying areas where you perceive that there are gaps**
- How you see the future for yourself as a carer over the next 10 years
- What you would like to see in place to support you as a carer over the next 10 years

At this point, ask for questions on points of clarification.

Timing and other issues

- Discussion group will last for 1 hour and 30 minutes
- Respect for everyone's views
- Allow people to speak without interrupting
- Ask for mobile phones to be switched to vibrate if possible
- Breaks to use the facilities, recharge etc
- Right to withdraw at any time
- Assurances of confidentiality

Part Two - Storytelling (30 minutes)

Paired discussion - grouped around specific themes arising from literature review, around the following themes for example (to be written up on a flip chart for the facilitator and members of the group to refer to as a prompt/guide to the discussion)

Type of care experience (e.g. strokes, cancer, mental illness)

Co-ordination of care services (e.g. description of care journey between primary and secondary care services and experiences of support services at different stages, e.g. diagnosis, treatment, after treatment, barriers to care, where things work smoothly, where they do not and reasons why they do)

Specific issues in relation to BME carers (meeting the needs, cultural barriers to accessing care services, specific focus on religious beliefs and provision of care services, religious/cultural practices, also religious/cultural practices when the person cared for dies)

Provision of information (e.g. carer views on information and communication, written/verbal on becoming a carer, during, adequacy of information, timeliness, appropriateness, clear/understandable, literacy and language issues, assistance in understanding)

Effectiveness of policies to support carers (e.g. respite care, availability of care breaks)

Employer based support for carers (e.g. flexible working policies, availability of care breaks, impact of flexible working on earnings, progression, career trajectory, pay differential between male and female carers and contribution to the pay gap, career prospects for young carers, representation in employment sectors, influences on full and part time working)

Education (experience of being a young carer, impact on education and employment prospects, impact of caring on opportunity to participate in learning/life-long learning/returning to the labour market after caring responsibilities come to an end)

Spiritual support/Social support/Psychological support (e.g. whether spiritual/social/psychological needs of carers are recognised as well as considered by service providers)

This stage to involve groups of carers in pairs telling their individual stories about their experience of being a carers, how it feels to be in the shoes of a carer, the needs of a carer,

the barriers faced by carers, how these are overcome, the impact when they cannot be overcome, what is an ordinary week in the life of a carer, what makes it a good week or not a good week, how likely the current situation is to improve or become worse in the future. During the storytelling, the other participant should log the key points of the story and then the roles should be reversed.

Feedback - 2 minutes per participant (maximum of 12 participants per group) and structured on a flipchart by the facilitator in terms of the issues identified above.

Part Three - Futures Exploration (30 minutes)

In this session, participants will work in groups of 4. It will involve a series of vignettes customised to each focus group. This will provide the context for a discussion about the future needs of carers, and given their current experiences detailed in Part two above, how this impacts on their future/how they perceive their medium term and long-term future as carers. The focus will be on how they as carers see themselves in the next 10 years, and what in their experience needs to be considered/change over the next 10 years in terms of support services for carers.

Feedback – 3 minutes per group and structured on a flipchart by the facilitator.

Conclusions (15 mins)

Opportunity for participants to raise issues in relation to the study and their experiences that were not covered above, or points that they would like to reiterate.

Thank you to participants for their contributions and payment of incentives

Annex B: Topic guide used for carers with mental health problems and learning difficulties

Focus upon:

- What in your experience works well
- What in your experience does not work well
- What in your view needs to be improved and how
- Identifying areas where you perceive that there are gaps
- Looking to the future – how you see life as a carer over next 10 years
- What areas you feel need to be improved upon

Type of care experience

relationship to you
condition of person cared for (if appropriate)
how long etc

Co-ordination of care services

description of journey between primary and secondary care services
experiences of support services at different stages, e.g. diagnosis, treatment, after treatment,
where things work smoothly – reasons why
where they do not - reasons why

Provision of information

written/verbal information available on becoming a carer, and during,
adequacy of information,
appropriateness,
clear/understandable,
literacy and language issues,
assistance in understanding

Effectiveness of policies to support carers

e.g. respite care, availability of care breaks

Employer based support for carers (where applicable)

e.g. flexible working policies, availability of care breaks, impact of flexible working on earnings,
progression, career trajectory, pay differential between male and female carers and
contribution to the pay gap, career prospects for young carers, representation in employment
sectors, influences on full and part time working

Education (where applicable)

experience of being a young carer, impact on education and employment prospects, impact of caring on opportunity to participate in learning/life-long learning/returning to the labour market after caring responsibilities end

Spiritual support/Social support/Psychological support

e.g. whether spiritual/social/psychological needs of carers are recognised as well as considered by service providers

Specific issues in relation to MH carers

How has your condition affected care services?

What support is available for you?

How effective do you feel this has been?

What can be done to improve?

Future as carer over next 10 years

How you see the future for yourself as a carer over the next 10 years

What you would like to see in place to support you

Given experiences above - how this impacts on their future/how they perceive their medium term and long-term future as carers

What needs to be considered/changed over the next 10 years in terms of support services for carers

Conclusions

What carers enjoy about caring (end on positive note)

Opportunity to raise issues in relation to the study and their experiences, not covered above, or points that they would like to reiterate

Thank you, collect travel receipts, hand over project info etc

Appendix 5:

**National household survey
in Scotland on issues
related to unpaid care**

1. Introduction

1.1 The Omnibus Survey

OPM, in conjunction with Scottish Opinion, conducted a national household survey, in order to hear the experiences of people who currently care and to find out about the general public's perceptions of caring, the expectation and perceived likelihood of themselves being carers in future and their expectations of support services and how care should be provided.

As such, sixteen questions were inserted into Scottish Opinions weekly omnibus survey. Overall 1,007 interviews were conducted with the general public in Scotland between Tuesday 24th November and Tuesday 30th November 2004. Telephone interviews were conducted with respondents in all 73 Scottish Parliamentary constituencies and results were weighted according to gender, age and socio-economic group to ensure that the final sample is representative of Scotland's population.

All responses were analysed anonymously and the results of this survey are given in this report.

The questionnaire is attached in the Annex.

1.2 Methodological issues

Where relevant totals do not equal 100 per cent this is due either to non-response or computer rounding.

Unless otherwise stated, no significant variations in responses were found between sub-groups. Comparisons sometimes proved difficult due to the small number of responses in some sub-groups and for this reason any comparisons made should be treated with some caution.

The report details respondents perceptions, rather than facts. The verbatim comments throughout are meant to be illustrative rather than in any way statistically representative.

2. Sample profile

The sample of 1007 respondents who took part in the survey is profiled in the table below.

Due to small discrepancies between the sample obtained and the actual population, weighting has been applied to the data to reflect the profile of the population in Scotland.

The sample includes marginally more females (52%) than males (48%).

A broad range of age groups are represented, with 21% of respondents under 35 years old, 36% aged between 35 and 54 years old and 33% aged 55 years or older.

In terms of socio-economic grouping, approximately half (47%) of respondents were within the more affluent ABC1 classifications, whilst the other half (53%) were classified within the C2 and DE groups.

Table 2.1: Sample profile

	Number of respondents (weighted) N	Sample profile (weighted) %
All respondents	1007	100
Gender		
Female	527	52
Male	481	48
Age		
18-24	113	11
25-34	197	20
35-44	199	20
45-54	161	16
55-64	133	13
65+	205	20
Socio-economic group		
AB	187	19
C1	282	28
C2	201	20
DE	337	33

Region

	Number of respondents (weighted) N	Sample profile (weighted) %
Central	66	7
Dumfries	34	3
Fife	69	7
Grampian	83	8
Highlands and Islands	88	9
Lothian and Borders	165	16
Strathclyde	430	43
Tayside	73	7

In order to find out what proportion of the overall sample were currently carers, the survey began by asking respondents whether there was anyone either living with them or living in another household who has problems with their physical health, has a disability, is suffering from mental ill health or is elderly, whom they look after or give special help to, other than in a professional or financial capacity.

Out of all the respondents, 88% said that they were not carers. These respondents were asked about their general perception of caring, the expectation and perceived likelihood that they would become carers in future, and their expectations of support services and how care should be provided (i.e. by the family, the state or the voluntary sector). Responses to these questions are detailed in section four below.

Twelve per cent of all respondents said that they were carers, according to the definition provided. This figure is representative of the national picture: previous research has found that 12% of the population in Scotland have caring responsibilities.¹ Of those respondents who said they were carers, half (49%) said that the person they cared for lived with in their household, and the other half (51%) that the person lived in another household.

Table 2.2: Proportion of carers

	Total %
Yes – living with me in my household	6
Yes – living in another household	6
No	88
Base (1007)	

¹ Scottish Household Survey 2001-2002.

3. People who provide care

3.1 Profile of carers

As shown in table 3.1 below, women were more likely than men to be a carer. Two-thirds (66%) of respondents who were carers were women.

The data suggests that the likelihood of being a carer rises and then subsequently falls with age.

Respondents from higher socio-economic groups (AB and C1) were just as likely to be carers as respondents from lower socio-economic groups (C2 and DE).

The demographic profile of carers interviewed during this survey, as detailed below, is similar to the national profile of carers found in previous research.^{2 3}

Table 3.1 Profile of carers

	Number of respondents N	Sample profile %
All respondents	118	100
Gender		
Female	78	66
Male	40	34
Age		
18-24	14	12
25-34	16	14
35-44	19	16
45-54	26	22
55-64	25	21
65+	17	14
Socio-economic group		
AB	17	14
C1	38	32
C2	23	19
DE	39	33

² “2001 Census Policy Briefing” Carers UK, available at <http://www.carersonline.org.uk>

³ ‘Informal Care of the Elderly in Scotland and the UK’ Scottish Executive Central Research Unit (2001)

3.2 Who they care for

As illustrated in table 3.2 below, respondents who provided care in an informal capacity were most likely to provide care for either a parent or parent-in-law (40%); partner, husband or wife (25%); and/ or their child or children (own/ adopted/ step/ foster).

Smaller numbers of respondents provided care for a friend or neighbour (9%), a grandparent (6%) or someone else such as a sibling, grandson, uncle, aunt, brother-in-law and/ or cousin (10%).

The majority of respondents who provided care did so for one person (81%); nevertheless, nearly a fifth (18%) of respondents said they provided care for more than one person.

Table 3.2: Who do you care for in your capacity as a carer

	Total %
A parent or parent-in-law	40
My partner/ husband/ wife	25
My child/ children (own/ adopted/ step/ foster child)	15
A friend/ neighbour	9
A grandparent	6
Someone else	10
Unsure	1
Base (118)	

Of those respondents who provided care for their child or children, almost three-quarters (72%) said that the child was under the age of 18 and a third (33%) that the child was over 18 years old.

3.3 Levels of care provided

Type of care

As shown in table 3.3, the majority of the carers in this survey provided practical help, such as shopping, laundry, gardening and travel to appointments (85%) and other assistance such as keeping the person company, visiting, reading and making sure that they are alright (84%).

Other care provided by over half of carers included: helping with paperwork such as dealing with bills, forms or their banking (64%); going out, such as taking them for a walk or drive or to see friends (61%); and providing physical help such as walking, using the stairs and getting into and out of bed (51%).

A smaller but still significant proportion of carers also provided more personal care, such as dressing, bathing, washing, eating and using the toilet (37%); and giving medicines or administering pills, injections and changing dressings (35%).

Table 3.3: Type of care provided

	Total %
Other practical help e.g. shopping, laundry, gardening, travel to appointments	85
Keeping them company, e.g. visiting, reading, making sure they are alright	84
Helping with paperwork e.g. dealing with bills/forms/ banking	64
Going out, e.g. taking them for a walk or drive or to see friends	61
Physical help e.g. walking, using the stairs, getting into and out of bed	51
Personal care e.g. dressing, bathing, washing, eating, using the toilet	37
Giving medicines or administering pills, injections, changing dressings	35
Other	6
Base (118)	

A number of respondents (6%) also mentioned other help that they provided, including:

- *Preparing meals*
- *Answering phones*
- *Arranging for other carers when they are busy*
- *Decorating*
- *Giving dietary advice and checking to see that they are eating properly*
- *Getting prescriptions from the chemist*
- *Providing therapy (due to dyslexia and autism)*
- *Helping with spatial awareness.*

Average time spent caring

In an average week, approximately half (40% 0-19 hr/wk & 9% Varies – under 20 hrs) of the carers in this survey spend less than 20 hours looking after or helping the person that they care for, whilst the other half (49%) provide care for more than 20 hours a week, with 18% of respondents actually caring for 50 hours or more. This includes the types of specific provision cited above, and also times when they feel that they just need to be there.

These results are shown in table 3.4 below.

Table 3.4: Average time spent looking after or helping the person cared for

	Total %
0-19 hr/wk	40
20-34 hr/wk	18
35-49 hr/wk	9
50-99 hr/wk	2
100+ hr/wk	16
Varies – under 20 hr	9
Varies – 20+ hr	4
Unsure	1
Base (118)	

Length of time as a carer

Amongst the carers interviewed during this survey, two-fifths (41%) had started caring within the last five years, around a third (30%) had been caring for between 5 and 10 years, and the remaining quarter (27%) had been caring for longer than 10 years.

Table 3.5: Length of time respondent has been looking after or helping the person they care for

	Total %
Less than 6 months	2
6 months, less than 1 year	5
1 year, less than 3 years	21
3 years, less than 5 years	13
5 years, less than 10 years	30
10 years, less than 15 years	7
15 years, less than 20 years	11
20 years +	9
Unsure	1
Base (118)	

Other assistance

Respondents were asked whether, apart from people such as nurses or home carers who may visit regularly, anyone else helped to look after the person – for example, another member of their household, another member of the family, a relative or friend or some kind of paid helper.

Over two-fifths (42%) of those respondents who were carers said that they did not have such assistance.

Table 3.6: Proportion of carers

	Total %
Yes	57
No	42
Unsure	1
Base (118)	

As illustrated in table 3.7 below, all of those respondents who received help to look after the person did so from a relative or a friend, with the most common sources of assistance being either a sibling (39%) or a partner or spouse (16%).

Table 3.7: Other people who help to look after the person cared for by respondent

	Total %
My sister/ brother/ other sibling	39
My partner/ husband/ wife	16
Child of person I care for	9
Neighbours or friends	9
My mother or father	7
Aunt or uncle	5
Daughter or son	4
Cousin	1
Someone else	13
Base (67)	

3.4 Impact on carers

Health

Carers were asked whether or not they had experienced any of the symptoms listed in table 3.8 (below) as a result of being a carer. The findings suggest that caring has had a detrimental effect on the general well being of the majority of respondents (63%), at least to some extent.

Four in ten carers said that they suffered from a general feeling of stress as a result of being a carer (41%) and the same number again said that they suffered feelings of tiredness (40%).

Approximately three in ten respondents reported feelings of anxiety (31%), irritability (29%) and/or disturbed or lack of sleep (28%).

Sixteen per cent of carers reported suffering from physical strain (e.g. back) and 13% reported a loss of appetite due to their caring responsibilities

Table 3.8: Symptoms experienced a result of being a carer

	Total %
General feeling of stress	41
Feeling tired	40
Feelings of anxiety	31
Short tempered / irritable	29
Disturbed / lack of sleep	28
Feeling depressed	21
Physical strain (e.g. back)	16
Loss of appetite	13
In other ways	1
No, carer's health not affected	37
Base (118)	

Further to this, as shown in table 3.9 below, a quarter (25%) of all respondents who identified themselves as carers said that they had had to visit their GP in the last 12 months due to their health being affected by their role as a carer.

Table 3.9: Whether respondent had had to visit their GP in the last 12 months due to their health being affected by their role as a carer

	Total %
Yes	25
No	75
Base (118)	

Personal and social

Respondents were then asked whether or not their personal or social life had been affected in any of the ways listed in table 3.10 (below) as a result of being a carer. Caring had a negative impact on the personal and social lives of a significant number of these carers (54%).

The most commonly cited issues were a lack of free time e.g. for personal interests and hobbies (40%); other aspects of their family life having to take a back seat (25%); financial problems (20%); and caring having had an adverse affect on their career (18%).

Carers in the youngest age group (18-24 years old) were much more likely than other age groups to say that that being a carer had adversely affected their career (56%) and their education (44%).

Those respondents who were least likely to state that caring had affected their personal or social life were carers over the age of 65 (72%).

Table 3.10: Ways in which personal life of carer has been affected

	Total %
Lack of free time (e.g. for personal interests and hobbies)	40
Other aspects of my family life have had to take a back-seat	25
Financial problems	20
Adversely affected my career	18
Lonely / feeling isolated	15
Adversely affected my education	10
In other ways	6
No, my personal/ social life has not been affected	43
Unsure	3
Base (118)	

A small number of respondents also cited other areas of their personal and social lives that have been affected by caring, including:

- *No holidays*
- *Pressure and restrictions impacting on the younger members of the family*
- *Lack spontaneity in planning free time, need to have constant awareness of facilities available*
- *Used to go out at weekends but now we can't actively participate in events*
- *Not having freedom of choice.*

Breaks from caring

Short breaks from caring are known to have positive benefits for the carers and the person they care for. The survey went on to ask what sort of arrangements respondents had used when they last had a break from providing care for two days or more.

Only one in eight (12%) of those people interviewed said that they had benefited from formal respite or care break arrangements when they last had a break from providing care for two days or more. The arrangements used included an arranged holiday for the person and carer (5%); a nursing or residential home (3%); an NHS Hospital (2%); an arranged holiday for only the person cared for (1%); or a local authority hospital (1%).

A further third (34%) of respondents said that, although they had managed to have a break from providing care for two days or more, they had to rely on friends or relatives to take on their caring responsibilities. Others (3%) had to make do as best as they could, including:

- Asking the home help and formal paid carers to fill the gaps
- The person being cared for having to manage on their own.

Over a third (36%) of respondents said that they had not had such a break. The vast majority (29%) of these respondents said that this was because it had not been required. However, the remaining 7% had not had such a break because they did not know how to access it.

Table 3.8: Types of arrangements used when respondent last had a break from providing care for 2 days or more

	Total %
Arranged break or respite	
Arranged holiday (person & carer)	5
Nursing or residential home	3
NHS Hospital	2
Arranged holiday (only person cared for)	1
Local Authority Hospital	1
Stay with a volunteer family	0
Relied on relatives or friends to provide care	
Friend or relative staying with person cared for	20
Stay with relatives or friends	11
Other	3
Not had such a break	
Not had such a break because we have not required it	29
Not had such a break because I do not know how to access	7
Was offered such a break but it was not suitable for our needs	0
None / unsure	16
Base (118)	

3.5 Support from relevant agencies and organisations

The survey asked respondents whether or not they thought there were any organisations that should support them in their role as a carer, and if so what those organisations might be.

A staggering 58% of respondents did not think there were any organisations that should support them in their role as a carer; and a further 17% were unsure. Without further information, it is difficult to interpret this finding. Perhaps carers have received little help for so long they have come not to expect it, or perhaps they just do not know what support they should be entitled to.

Of those respondents (25%) who did think that there were organisations that should support them, in their role the most commonly cited organisations were the local authority and the government.

A number of respondents felt that their local authority should be less bureaucratic about the need for assistance and should provide more than the minimum services. Carers felt the local authority should provide better trained staff, increased home help and more respite care and relief cover. Further to this, it was suggested that the local authority should provide training for carers, including informing them of their rights.

The government was seen to have a duty to improve carers' financial situation, and financial issues were a major concern for many carers. Carers also said that the Government should provide more information and education in terms of awareness raising campaigns, and should be more proactive in telling people what they are entitled to.

A number of carers named specific organisations, often linked to the condition or illness of the person they care for, such as the Epilepsy Association, Macmillan Nurses and the Parkinson's Society, and simply requested that they help out a bit more sometimes.

Finally, some respondents stated that they wanted more emotional support but were unaware of organisations they could approach to provide it: *'Probably just a bit of moral support, reassurance but not aware of organisations available to assist'*.

3.6 Rewarding aspects

Finally, carers were asked about the rewarding aspects of being a carer. The range of the comments made are given below:

Sense of satisfaction and achievement

- *Being able to help and feeling that you're able to do something for someone*
- *Knowing the person is alright*
- *Knowledge that your helping out is satisfying*
- *Seeing the person happy*
- *Helping someone is more rewarding than anything else, doing something for them that they can't do, people are generally grateful*
- *Makes you a better person.*

Family

- *Giving back what has been given to you over the years, makes you feel good*
- *See them getting better*
- *Strengthens family relationships/ Brings you closer to the person who you are caring for*
- *Receiving lots of love*
- *Doing stuff for my grandparents gives me a sense a achievement*
- *That's what your family is there for, to look after each other.*

Helping the person you care for achieve quality of life

- *Just seeing him getting on with it and seeing him happy even if it is for a short time*
- *Just being there for her, knowing that she is being able to lead as normal a life as she can*
- *Knowing that your enjoying something good for the person, and being there for the person, enjoying your time with the person*
- *Making them feel independent*
- *Seeing that person gain independence*
- *To see them getting on with their life*
- *You can see the practical effect*

Sense of duty

- *At least you know it's done*
- *It's a duty or responsibility*
- *Still have them to care for*
- *Take care of own child*
- *Don't burden others*

Company and benefit to the carer

- *He's still here and that's the most rewarding part of it*
- *I know I'm doing the best I can do at the time, you know they are getting looked after, that gives you a buzz*
- *It makes my mother happy, and I like to see her out and about in her wheelchair*
- *Keeps you busy, dressings to do every day, stockings that have to be done, cooking, and that my husband is still here, would be a very lonely life without it*

Some respondents, however felt that there were no rewarding aspects to being a carer:

- *Negative outweigh positive*
- *None*

4. Respondents who are not carers

Of all respondents to the survey, 88% were not carers as per the definition provided (i.e. there was no one either living with them or living in another household who had problems with their physical health, had a disability, was suffering from mental ill health or was elderly, whom they look after or give special help to, other than in a professional or financial capacity).

4.1 What does it mean to be a carer?

Over one in five (22%) of respondents who were not carers themselves did however know someone who is currently a carer.

Irrespective of whether or not they knew someone who was a carer, respondents were asked to say, in their own words, what they thought being a carer for a relative or a friend meant.

The vast majority of respondents defined this generally in terms of '*Looking after someone who is unable to cope themselves*', whilst some defined it in more detail as '*basically looking after their every need, making their meals, making sure they are comfortable, washing, shopping*'.

However many respondents also referred to the emotional, loving and supportive aspects of being a carer:

- *Give them all the love and care you can, being their support*
- *Looking after them, attending to their needs, physically and mentally, and financially and spiritually.*

Many viewed caring in terms of a family scenario i.e. caring for a close relative:

- *Something that's supposed to happen*
- *That's what a family is for – caring for each other*
- *To be kind to them because they're your family!!*
- *A lot of commitment, if its a family member you do it out of love for the person*

Some respondents felt that providing financial help was also an aspect of being a carer:

- *Providing either financial assistance or looking after someone*
- *Providing emotional and financial help*
- *Taking care on a financial basis*

In addition a large majority of respondents also felt that it was a task that would be *'very hard and trying and very, very difficult'*, with some respondents commenting on how hard it must be to be a carer:

- *Demanding and difficult*
- *Pretty tough*

Many saw caring as a *total commitment* and felt that the carer would need to make sacrifices in terms of their time, social life and or career; some referred to putting your own life on hold:

- *Coping with the extra responsibility, not having enough time for yourself, not much of a social life, stuck in the house some days*
- *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*
- *Giving up a lot of your time, money, to look after the person because they're unable to do so, a very Christian thing to do*
- *Someone who sacrifices aspects of their own life in order to care for someone related to them on a 24 hours a day basis*

There were also comments made on the physical strain caring would entail:

- *Quite a lot of physical strain to both the carer and the person, and a lot of stress*
- *Quite hard work, can be quite heavy*

Although the majority of respondents saw caring in terms of an adult having to look after a relative, one respondent also referred to children as carers:

- *I've seen a lot of hard work, I suppose it can be really rewarding at times as well, but it is hard work and very little time to yourself, particularly difficult for children to be carers*

Many respondents also raised the issue of the lack of support available to carers:

- *It's a lot of hard work, and a thankless job that doesn't get outside support*
- *Putting your own life on hold while you care for them, become everything to them, their eyes and ears, you do it out of love, but frankly it is a 24 hour job with no support at all.*
- *Absolute nightmare, need to wait until there is an extreme crisis until you get help of any kind*
- *A lot of jolly hard work, giving up personal things. Government haven't got a clue*

4.2 Likelihood of becoming a carer

The survey went on to ask respondents who were not currently carers how likely it was that they might become carers within the next 10 years.

As shown in table 4.1 below, 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). Nevertheless, approximately one in seven (15%) respondents said that it was either very or quite likely.

In terms of age groups, the highest proportion of those respondents who thought that they were likely to become carers within the next 10 years were in the 45-54 (26%) and 35-44 (22%) age groups. A higher proportion of women (19%) also thought that this was likely compared to men (11%).

Table 4.1: Likelihood of non-carers becoming carers within the next 10 years

	Total %
Very likely	4
Quite likely	11
Neither / nor	5
Not very likely	34
Not at all likely	38
Don't know	7
Base (890)	

Those respondents who said it was either very or quite likely that they would become carers within the next 10 years were then asked what concerns, if any, they would they will have about becoming a carer.

As illustrated in table 4.2 below, the main concerns were the effect on their personal and social life (31%) and the effect on their career (23%).

One in five (20%) respondents were also worried about the effect caring might have on their health and well-being, and the same number (20%) again expressed concern about the financial aspect of being a carer.

Respondents in the 18-24 age group (53%) and men (40%) were more likely than others to be concerned about the possible effect caring could have on their career.

Table 4.2: Concerns about becoming a carer

	Total %
The affect on my personal/social life	31
The affect on my career	23
The affect on my own health / well being	20
The financial aspect of being a carer	20
Other	27
None	27
Unsure	3
Base (890)	

Over a quarter (27%) of respondents had other concerns. Examples of some of these concerns are given below:

- *Don't know if I'll cope*
- *Accessing facilities from the government and local authorities and being able to find what's available, e.g. medical assistance for people discharged from hospital*
- *Not knowing where the help is*
- *Physical and mental strain*
- *The availability of community services*
- *The affect on you emotionally*
- *Being capable of caring*
- *Having to relocate, and impact on other family members*

4.3 Responsibility for caring

Finally, the survey asked who respondents thought should have the main responsibility for providing care to an individual. The majority of respondents (51%) thought that it was the families' responsibility, and a further 30% that the local authority should have the main responsibility for providing care to an individual.

Some respondents mentioned an organisation, such as the government or the Scottish Executive, the NHS and charities, believing that they should have the main responsibility for providing care to an individual; others cited different combinations of all these organisations.

Table 4.3: Who should have the main responsibility for providing care to an individual

	Total %
The family	51
The Local Authority	30
Depends on individual circumstances	4
The family and the local authority	3
Charities	1
The government/ The Scottish Executive	1
The NHS	1
The family and the government	1
Combination of all	1
Voluntary Groups	*
Unsure	4
Base (890)	

Annex – Questionnaire

1. May I check, is there anyone either living with you or living in another household who has problems with their physical health, has a disability, is suffering from mental ill health or is elderly whom you look after or give special help to, other than in a professional or financial capacity
 - Yes - living with me in my household
 - Yes - living in another household
 - No – GO TO Q12 (not current carers questions)

- 2a. Who do you care for in your capacity as an informal carer: CODE ALL THAT APPLY
 - My partner / husband / wife
 - My child or own/adopted/step/foster child : ask age of child (Q2b)
 - A parent
 - A parent-in-law
 - A grandparent
 - A friend / neighbour
 - Someone else: please specify

- 2b. If child is cared for – please tell me the age of your child
 - Up to 5 years
 - Over 5 years up to 10 years
 - Over 10 years up to 15 years
 - Over 15 years up to 18 years
 - Over 18 years

3. How many people do you care for in your capacity as an informal carer? - CODE ONE ONLY
 - One
 - More than one
 - Unsure

- 4a. What kinds of things do you usually do for the person that you care for CODE ALL THAT APPLY.
Do you usually help with[READ OUT]
 - Personal care (e.g. dressing, bathing, washing, eating, using the toilet)
 - Physical help (e.g. walking, using the stairs, getting into and out of bed)
 - Helping with paperwork (e.g. dealing with bills / forms / banking)
 - Other practical help (e.g. shopping, laundry, gardening, travel to appointments)
 - Keeping company (e.g. visiting, reading, making sure you are alright)
 - Going out (e.g. taking you for a walk or drive, to see friends)
 - Giving medicines (e.g. administering pills, injections, changing dressings)
 - None of the above

- 4b. Is there any other help you provide? WRITE IN VERBATIM

5. About how long would you say that you spend in an average week looking after or helping the person you care for (in doing the things you've mentioned and including time when you just need to be there) PROMPT AS NECESSARY. CODE ONE ONLY
- 0-19 hours per week
 - 20-34 hours per week
 - 35-49 hours per week
 - 50-99 hours per week
 - 100 or more hours per week
 - Varies - Under 20 hours
 - Varies - 20 hours or more
 - Unsure
6. About how long have you been looking after or helping the person you are caring for. PROMPT AS NECESSARY. CODE ONE ONLY
- Less than 6 months
 - 6 months, less than 1 year
 - 1 year, less than 3 years
 - 3 years, less than 5 years
 - 5 years, less than 10 years
 - 10 years, less than 15 years
 - 15 years, less than 20 years
 - 20 years or more
 - Unsure
- 7a. Apart from any people, such as nurses or home carers, who may regularly visit is there anyone else who helps to look after the person you look after - for example, another member of your household, another member of the family, a relative or friend or some kind of paid helper? CODE ONE ONLY
- Yes
 - No
- 7b. If yes, please can you tell me who.... CODE ALL THAT APPLY
- My sister/brother/other sibling
 - Aunt/Uncle
 - Cousin
 - Child of person I care for
 - Neighbours
 - Private paid help
 - Someone else, specify.....
- 8a. What sort of arrangements did you use when you last had a break from providing care for 2 days or more? PROMPT AS NECESSARY. CODE ONE ONLY
- Nursing or residential home
 - NHS hospital
 - Local Authority hostel
 - Arranged holiday (PERSON cared for only)
 - Arranged holiday (PERSON and carer)
 - Stay with a volunteer family
 - Stay with relatives or friends

- Friend or relative staying with person cared for
- Not had such a break because we have not required it
- Not had such a break because I do not know how to access
- Was offered such a break but it was not suitable to our needs
- Other: please specify.....
- None/unsure

If code 11 at Q8a, ask Q8b

8b. You said that the break that you were offered was not suitable to your needs, could you please tell me why that was.... WRITE IN VERBATIM

9a. Have you experienced any of the following symptoms as a result of being a carer? CODE ALL THAT APPLY [READ OUT]

- Feeling tired
- Feeling depressed
- Loss of appetite
- Feelings of anxiety
- Disturbed/lack of sleep
- General feeling of stress
- Physical strain (e.g. back)
- Short tempered/irritable
- No, carers health not affected

9b. Has your health been affected in any other ways? WRITE IN VERBATIM

9c. In the last 12 months have you had to visit your GP due to your health being affected by your role as a carer? CODE ONE ONLY

- Yes
- No
- Unsure

9d. Has your personal/social life been affected in any of the following ways as a result of your being a carer? CODE ALL THAT APPLY [READ OUT]

- Adversely affected my career
- Adversely affected my education
- Financial problems
- Lack of free time (e.g. for personal interests and hobbies)
- Lonely/feeling isolated
- Other aspects of my family life have had to take a back-seat
- My life has been affected in some other way, please specify.....
- No, my personal/social life has not been affected
- Unsure

- 9e. What would you say are the rewarding aspects of being a carer? Please write in the box below –
WRITE IN VERBATIM

- 10a. Do you think there are any organisations that should support you in your role as a carer, and if so can you please tell me who those organisations might be? WRITE IN VERBATIM

For each organisation mentioned at Q10a, ask Q10b

- 10b. What do you think that this organisation could do to improve the quality of life for you in your role as a carer? COMMENTS CODED FOR EACH ORGANISATION MENTIONED - WRITE IN VERBATIM

- 11a. OPM has been commissioned by the Scottish Executive to undertake a wide ranging consultation on many aspects of the role and experiences of informal carers. If you would be interested in receiving information on this issue or you are interested in taking part in further discussion we will now ask you to provide your contact details. Your participation will help us to inform our work on the current issues faced by carers in Scotland and help to plan for the future. would you be happy to have your details passed on to OPM?
- Yes – I am happy for my contact details to be passed to OPM. I am aware that I do not have to take part in any further discussion.
 - No – I do not want my contact details to be passed to OPM.
- 11b. If yes, please collect full details of each respondent:
- Name
 - Full postal address (inc. postcode)
 - Telephone number (inc. std code)

(Ask if not current carer)

So if we are defining a carer as someone who has extra responsibilities because they look after someone who has long-term physical or mental ill health or disability, or problems related to old age...

12. Do you know anyone who is currently a carer? CODE ONE ONLY
- Yes
 - No
 - Unsure
13. What do you think being a carer for a relative or friend means? WRITE IN VERBATIM
-
14. How likely is it that you may become a carer within the next 10 years? CODE ONE ONLY
- Very likely
 - Quite likely
 - Not very likely
 - Not at all likely
 - Don't Know
15. If very or quite likely – what concerns, if any, do you think you will have about becoming a carer? CODE ALL THAT APPLY
- The affect on my own health / physical well being
 - The affect on my personal / social life
 - The financial aspect of being a carer
 - The affect on my career
 - Other: what are these.....
 - Unsure
16. Who do you think should have the main responsibility for providing care to an individual? PLEASE CODE ONE ONLY
- The family
 - The Local Authority
 - Voluntary Groups
 - Charities
 - Other, please specify.....

Many thanks for completing this survey

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