We are delighted to have the opportunity to contribute to this important Bill. Carers Scotland is a campaigning charity working with and for unpaid carers. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Many of the issues highlighted in the Bill will have a direct impact on carers. There are 660,000 carers in Scotland, 1 in 8 of the Scottish population. 374,800 of carers are of working age\(^1\). 110,000 carers provide 50 or more hours of care each week. 178,000 people become carers every year. Carers save the Scottish economy an estimated £7.6billion each year\(^2\).

Three out of five people in Scotland will become carers at some point in their lives\(^3\) and it is estimated that, as a result of demographic change, there will be 1 million carers in Scotland by 2037. Caring is an issue that will affect most of the Scottish population.

Carers give so much so society, yet as a consequence of caring, they experience ill health, poverty and discrimination. Our proposals if implemented and the effective inspection and improvement of services in Scotland have the potential to have a profound impact on the lives of carers, reducing the negative effects they experience.

**Public Services Reform (Scotland) Bill**

Carers Scotland’s response does not include all questions highlighted but focuses on the value of the bill, issues around part 6 (scrutiny) and parts 4 and 5.

We believe that despite the current financial climate there is value in pursuing this Bill and the wider public services reform programme. The value of ensuring that services are of good quality, that they provide good outcomes for service users and unpaid carers and that services providers are encouraged to focus on continuous improvement cannot be underestimated and is not solely dependent on finances.

This reflects the view of carers in a range of research. Most recently Audit Scotland\(^4\) reported that service users and carers reported that mental health services were not delivered to a consistent standard and earlier research in 2007 found that a third of carers felt that services were not reliable, nearly half felt they were not flexible or sensitive to their needs.\(^5\) Carers reported that some services,

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\(^1\) Census 2001  
\(^2\) Valuing Carers, Carers UK, 2007  
\(^3\) It Could Be You, Carers UK, 2002  
\(^4\) Overview of mental health services, Report supplement: Carers and service users views Audit Scotland, May 2009  
\(^5\) Carers, Employment and Services in Scotland: focus on East Ayrshire, Falkirk and Highland, Carers UK 2007
for example, respite and short break services had a negative effective or no beneficial effect.\(^6\)

The simplification of public bodies has much to recommend it. Carers and service users will have more clarity about which body has responsibility for inspecting and improving services that they use. However, it is critical that in seeking to harmonise and rationalise the conflicting demands on service providers from the inspection processes that the good practice developed by the different agencies is not diluted. Moreover, we would note that it is essential that there are clear routes of communication between the Social Care and Social Work Improvement Scotland and Health Improvement Scotland. Carers and the people they care for often utilise a range of health and social care services which often overlap and it is essential that there is clear information and communication on who retains responsibility in the event of issues arising.

### Part 4 – Social Care and Social Work Scrutiny and Improvement Establishment of Social Care and Social Work Improvement Scotland (SCSWIS)

Carers Scotland welcomes the duty upon this body to continue to provide information to public on quality of care services (41(1)) and its advisory role. We believe it will be beneficial to carers for SCSWIS to have its specific duty to provide advice to people or groups representing those who use care services or those who care for those who use care services. It is essential that carers have a clear route for to obtain information (41(3)) and that there is public dissemination of information to raise awareness of the work of SCSWIS and the quality of care services in Scotland. Research continues to highlight the need for better information to help people access the services they need.\(^7\)

However, we have concerns around point 41(4) stating that a fee may be charged to service users or carers who have requested advice. We know from the evidence of research that carers face poverty, inequality and deprivation as a direct consequence of their caring role. Recent research\(^8\) has identified that three out of four carers are significantly worse off as a result of caring, rising to four out of five amongst those aged 45-54. This is exacerbated by the extra costs of disability, including heating costs and service charges, with more than half of carers subsidising the costs of the disability of the person they care for because of inadequate disability benefit. Carers Scotland believes that paying for essential information can be a strong disincentive to carers and those they care in seeking advice, support and in finding information on the right service for them.

Carers Scotland welcomes the clear focus on evaluating the effectiveness of services and that continuous improvement is encouraged. We warmly welcome the proposal to continue to ensure that service users and carers are involved in the process of inspection. The evidence from our partnership with the Social Work

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\(^6\) Supported to Care, Princess Royal Trust for Carers and Crossroads Caring Scotland, Glasgow Caledonian University 2007

\(^7\) Overview of mental health services, Report supplement: Carers and service users views Audit Scotland, May 2009

\(^8\) Real Change not Short Change, Carers UK, 2007
Inspection Agency suggests that the involvement of carers as lay inspections in the inspection of social work services has been both positive and productive. However, given the fact that it is estimated there will be 1 million carers by 2037, we would prefer that there be included a statutory duty to involve carers in this way. However, minimally agencies should be required to give good reasons for not involving carers. The presumption should be that they will be involved. (Inspections (443 (2))

Whilst supporting the SCSWIS aim to provide clear public information, we believe that inspection information should be made available online. However, Carers Scotland would prefer a statutory duty for service users and their carers be informed if an improvement notice is issued to the service which they use. (Improvement Notices (51))

Furthermore, Carers Scotland welcomes clear information on SCSWIS requirement to have a clear procedure and publicity protocols for carers and those using services to make complaints. However, we would like to see the requirement on statutory service providers to have their own complaint procedure, extended to all service providers. If non statutory bodies do not have a complaint procedure, carers and service users have no clear route to resolving difficulties or issues. The increasing use of direct payments makes this all the more important. (Complaints (64))

Enabling carers and those they care for to have the information they need to make informed choices about the services which they use are essential. The right service of the right quality can enable carers to have an “ordinary life”. At present many carers are excluded from the world of work, leisure and learning. For example, more than half of carers providing 50 hours or more or care of work have given up work to care with one in five reducing the hours they work as a consequence of caring. Two out of three working age carers are not in paid work with one if four unable to work because of their own sickness or disability. Nearly two thirds of working age carers have no-one in their household in paid work. This proportion increases to nearly nine out of ten where the carer is looking after their partner. 9 This has an impact on all areas of carers’ lives including finances. Recent research10 found that carers in Scotland lost an average of £11,000 as a result of caring – by giving up work, reducing hours, retiring early or as a result of reduced career prospects. Seven out of ten carers say their caring responsibilities affect how much they could earn and one in seven say that their being a carer reduces the earning ability of others in the household. In addition, on average, carers retire 8 years early, missing out on years of income and pension contributions.

Part 5 – Health Care Scrutiny and Improvement Establishment of Health Improvement Scotland (HIS)

Carers Scotland welcomes the establishment of Health Improvement Scotland and its clear focus on improvement. The principles specified in ensuring that safety and wellbeing of those using health services is at the heart of the new body’s

9 Out of Pocket, Carers UK, 2007
10 Out of Pocket, Carers UK, 2007
functions are very positive. We further welcome a focus on ensuring that good practice is identified and promoted. This further supports the aim of improving services. (10B).

Carers are a third more likely to be in poor health than non-carers, with this proportion increase to twice as likely in some areas of Scotland. In a recent research\(^\text{11}\), more than three-quarters of those carers questioned felt that their health is worse as a result of the strain of caring. A large majority of carers admitted to feeling ill, anxious or exhausted, with a staggering 95% of those questioned saying they regularly cover up or disguise the fact that their health is suffering in order to continue with their caring responsibilities. Worryingly, one-fifth of these carers said they ignored feeling ill "all the time". Almost 1 in 4 carers said they frequently feel unable to cope with their day-to-day duties due to the physical and emotional stresses of their caring role.

The role of health services is critical to supporting unpaid carers in their caring role. Effective inspection and service improvement is key to preventing ill health amongst the caring population. The Social Work Inspection Agency model of self-evaluation provides an effective means of identifying, promoting and implementing health improvement.

Carers Scotland welcomes the duty to provide information to public on the availability and quality of services (10C3). As noted earlier, research continues to highlight the pivotal role of information and the need for better information to enable carers and those they care for to make informed decisions. As noted under our comments on SCSWIS, we welcome that the body will have a specific duty to provide this information to people or groups representing those who use health services or those who care for those who use health services. (3) However, we again have significant concerns that a fee may be charged to service users or carers who have requested information (10C4). As noted earlier, we believe that paying for essential information can be a strong disincentive to seeking advice and support.

Health Improvement Scotland’s proposed focus on developing effective standards and good outcomes is a positive aim. We welcome the requirement that Scottish Government must consult with appropriate people and groups. However, some clarity on those who are “appropriate” may be of assistance. We believe however that this could be strengthened by specifically mentioning patients and carers. (10H)

Welcome the clear focus on evaluating the effectiveness of services and that continuous improvement is encouraged (10J). We believe that the modus operandi developed by the Social Work Inspection Agency has much to recommend it. In practice it has engaged authorities, has been generally participative and has been effective in achieving positive changed and improvement in service delivery and in identifying and promoting best practice.

\(^{11}\) Carers can’t afford to be ill, Carers Week consortium, 2008
As noted earlier under our response to SCSWIS inspection reports we would prefer ensuring that inspection reports are available online not just solely in HIS offices. We also believe that those involved in commenting on inspections – specifically patients and carers – should receive a copy and feedback on their contribution in evaluating services (10M). Carers Scotland believes that service users and their carers using the service should be informed if an improvement notice is issued (10Q)

Welcome clear information on HIS requirement to have a clear procedure and publicity protocols for carers and those using services to make complaints. However, as noted under our response to SCSWIS, we would like to see a requirement on services to have their own complaint procedure as part of the process. (10Z3)

**Part 6 - Scrutiny**

We welcome the clear intention of a user focus in ensuring and demonstrating continuous improvement. We further welcome the clear requirement to involve users in the design and delivery of scrutiny functions and that this requirement also includes unpaid carers representing those they care for. However, we prefer to see including an explicit statement that unpaid carers are involved. As noted earlier, the involvement of carers as lay inspectors in the Social Work Inspection Agency inspections and their inspection process in general offers a number of positive outcomes that can be developed to be included in the work of Health Improvement Scotland. (92)

Cooperation and communication between local authorities, health and social services is essential to any process that aims to secure continuous improvement and to ensure that services are responsive to carers and those they care for. (94)

We believe that the development of joint inspections is a sensible approach. However, as noted earlier we would prefer to see a requirement placed to specifically involve unpaid carers and service users. (95)

**Conclusion**

In summary, we are delighted to have the opportunity to highlight some of the key issues faced by carers. Many issues faced by carers are interlinked and effective inspection could have impact on more that one area of carers’ lives. We hope that carers can be fully involved in the new scrutiny bodies. We believe that the Social Work Inspection Agency inspection model which has proved to be a positive one is worthy of extension.

Carers Scotland  
August 2009

**About Carers Scotland**

Carers Scotland is an organisation of carers fighting to end the injustice of carer ill health, poverty and discrimination. We will not stop until people recognise the true
value of carers’ contribution to society and carers get the practical, financial and emotional support they need.

Carers Scotland is here to improve carers’ lives.

• **We fight for equality for carers.** We want carers to have the same rights as everyone to an ordinary life – a fair level of income, access to support to protect their health and wellbeing and access to the world of work, leisure and education.

• **We seek to empower carers.** We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of care.

Carers Scotland achieves this by:

• campaigning for the changes that make a real difference for carers.
• providing information and advice to carers about their rights and how to get support
• mobilising carers and supporters to influence decision makers.
• gathering hard evidence about what needs to change.
• transforming the understanding of caring so that carers are valued and not discriminated against.
• providing carer awareness training for staff in health, social care and the voluntary sector
• promoting training for carers to maximise their skills and experience.