



Carers Scotland response to Integration of Adult Health and Social Care in Scotland: Consultation on proposals

Carers Scotland is a charity set up to support the thousands of people who care for an elderly partner, sick friend or disabled family member. Carers Scotland is the Scottish nation office of Carers UK. Caring is part of life. Three in five of us will provide unpaid care for someone at some point in our lives. However, without the right support the personal cost of caring can be high with many carers experiencing poor health, poverty and disadvantage. Carers Scotland helps carers and campaigns to make their lives better.

Key facts about carers

- There are 660,000 carers in Scotland - 1 in 8 of the population
- 110,000 people provide over 50 hours of care per week
- The main carers' benefit is worth just £58.45 for a minimum of 35 hours.
- Three quarters of carers are struggling to pay utility bills and more than half are cutting back on food and heating to make ends meet.¹
- People from lower socio-economic backgrounds² and in areas of multiple deprivation³ are more likely to need and to provide care.
- Unpaid carers and young carers are more likely to suffer poor physical and mental health, particularly those who are providing intensive levels of care. This affects their ability to care.⁴

¹ Carers Scotland & Carers UK: Carers in Crisis (2008)

² EHRC, How Fair is Britain (2010)

³ Scottish Government & CoSLA, Caring Together – The Carers Strategy for Scotland (2010) and Scottish Household Survey

Carers Scotland welcomes the opportunity to respond to the consultation on integration of adult health and social care. We broadly welcome the proposals and our response intends to highlight key areas which we believe could be developed further to respond more effectively to the needs of carers.

Enhancing the case for change

Carers Scotland recommends that the case for change could be enhanced [at Chapter 1, 1.4] by including the following identified problems experienced by carers.

- Whilst delayed discharge is a problem, equally we would argue that people are **too often discharged from hospital without the necessary services and support in place** to enable them to stay safely at home. This causes unnecessary readmission to acute care and stress and burden on carers, affecting their physical and emotional wellbeing.
- Furthermore, care services for individuals and support to carers is often **only provided at a point of crisis**, resulting in poorer outcomes for both. Carers Scotland believes this is a critical problem to recognise and address within the proposals.
- Finally, whilst we recognise that integration proposals will initially focus on older people, the **inconsistency in the level of support provided to carers across Scotland is not particular to the care of older people**. However, in the case of care to older people, the impact on carers may be greater due to a significant proportion of these carers also being older e.g. spouse/partner carers.

Demographic considerations and carers

The demographic trend [Chapter 1, 1.9-1.1.5] towards an ageing population will also have a profound effect on unpaid carers which Carers Scotland believes should be further explored in national and local integration planning.

The need for carers will inevitably increase at the same time as it is predicted that over the next 20 years the UK economy will need another 2 million people in the workforce. This

⁴ Carers Scotland & Carers UK: Carers in Crisis (2008)

means that employers will need to widen their recruitment pool at the same time that society will see an increase in the need for care.⁵

Carers leaving employment involves high cost to the public purse. A recent study by the London School of Economics⁶ found that in England, the public expenditure costs of carers leaving employment in England amounted to £1.3 billion a year. This is made up of the cost of Carers Allowance of £0.3 billion and lost tax revenues of £1.0 billion (based on median full time earnings of £538 for men and £439 for women and part time earnings of £142 for men and £157 for women). There is no reason to believe that costs to public expenditure in Scotland would be significantly different, when adjusted to reflect population.

This is a conservative figure as it based only on the costs of Carers Allowance and lost tax revenue. Figures would be higher if carers are in receipt of other benefits e.g. income support and if lost national insurance is included.

In Scotland, approximately 178,000 people take up a caring role each year and 3 in 5 of us will become carers at some point in our lives. Taking on a caring role shouldn't mean a poorer quality of life or financial hardship; it should not mean that you have to give up work to care. A similar proportion of people will also cease caring and this means that many will be back in the position of seeking employment, perhaps after many years out of the job market.

Supporting individuals who take up caring, helping them to make that contribution and to lead a normal life outside of caring is an essential part of the solutions needed for the challenges ahead⁷.

In planning for integration it is vital that health and social care services must be organised in such a way as to ensure that not only do carers feel supported in their caring role and that their health and wellbeing is protected, **but that they are able to enjoy a life outside caring, including in employment, education, social and leisure activities.** Moreover, we believe that this approach applies equally to older people and other adults who use services and is in line with the priorities for public services outlined in the Commission for the Future Delivery of

⁵ TUC: *Full Employment – the next steps* (2004)

⁶ Dr Linda Pickard: *Public expenditure costs of carers leaving employment* (2012)

⁷ Carers UK. *A Manifesto for Carers.* (2005)

Public Services⁸ that *“public services are built around people and communities; their needs, aspirations, capacities and skills...”*

It is important to also recognise that, with a greater population of very old older people, there will be a greater proportion of carers who are also older. There is likely to be **an increased number of older carers** providing care for very elderly parents or other relatives, whilst still continuing to sustain employment into their late 60s (as outlined in the UK Government’s state pension planning). Moreover, there is also likely to be an increased number of older spouse and partner carers. We know that caring places significant demands on the health of older carers, particularly for those carers aged 75 and over, with these demands increasing further for those caring for 50 hours or more each week. It is therefore critical that integration planning includes measures to address the additional and distinct needs of older carers.

[Question 1]

Carers Scotland agrees that it is practical to focus initially on improving outcomes for older people, building on the experience of the Change Fund for Older People’s Services. However, integration should not be limited to older people as many people experience long term conditions and disabilities well before they reach 65. People of all ages should have holistic support to improve their lives and be offered choice and control over the support they receive, in line with the personalisation agenda. Moreover, to promote and encourage healthy older age, this support should not be reduced or limited as people age. Integration should aim to remove artificial divides between adult and older people services and maintain the level and range of support offered to individuals and their carers.

Carers Scotland agrees with the views of many other third sector organisations who contributed to the “Shared Statement of Adult Health and Social Care”⁹ that in planning to integrate health and social care for older people, *“it is vital that plans are not developed for older people then simply applied to younger adults whose needs are often very different.”* It is important that there is a clear and realistic timescale and framework for this further integration. It is vital that in integrating services for older people, plans for integration for all adults are not allowed to “drift” significantly. Furthermore, in focusing on outcomes for older

⁸ Report of the Commission on the Future Delivery of Public Services (2011)

⁹ Integration of Adult Health and Social Care in Scotland: Consultation – A shared statement from third sector organisations, July 2012

people we must not inadvertently fail to meet the needs of younger adults (who will be the next generations of older people) effectively. Holistic support at the earliest stage will help “*maximise healthy life expectancy and prevent or delay onset of ill health*”¹⁰ for individuals and their carers and thus more significant costs.

[Question 2 & 7]

Carers Scotland believes that the framework for integration is not fully comprehensive. In the first instance, the full involvement of housing and related services is critical to enable effective integration and the delivery of better outcomes for individuals and their carers. As outlined in the proposals [Chapter 1, 16 & 1.7] housing has a key role to play, particularly in supporting independent living. The proposals for integration would be enhanced by **formally** including housing and related services within all local Health and Social Care Partnerships. This should include including specified housing funds within integrated budgets. We believe that, to meet the needs of individuals and their carers holistically and equally across Scotland, formal involvement and accountability is needed.

Clarity is also required on the involvement of special health boards within the Partnerships. The role of, for example, NHS24 and the Scottish Ambulance Service and their related health and community services should be explored further.

Secondly, we believe that it is not sufficient to simply work in “close partnership” with the voluntary sector and carer representation. Partnerships must include a strong voice with **equal status** for carers and people who use services. Carers Scotland believes that the proposals would be greatly enhanced by including carer and service user representation as **voting members** on Health and Social Care Partnerships. Carers are equal and expert partners¹¹ in the provision of health and social care and, as such, have a vital contribution to make to the design, development and delivery of services in their locality. This is in line with priorities identified within The Commission for the Future Delivery of Public Services which recommended that key priorities for the delivery of services in the future must include

¹⁰ Integration of Adult Health and Social Care in Scotland: Consultation – A shared statement from third sector organisations (July 2012)

¹¹ Caring Together: A strategy for carers in Scotland, Scottish Government & CoSLA (2010)

“recognition that effective services must be designed with and for people and communities and not delivered “top down” for administrative convenience.”¹²

In line with the proposals within a “Shared Statement of Adult Health and Social Care”¹³ it is important that *“these representatives must be supported to be connected to a wider constituency and able to act as a conduit for people to influence strategic commissioning.”* Current structures for involvement and engagement in health and social care e.g. carer forums and patient involvement forums together with local carer organisations could support this effectively. (This structure would enable support for an alternate to attend a meeting should a carer be unable to attend e.g. due to caring issues). It is important to recognise that the needs of carers and of people who use services are distinct from one another and that representation should include both.

The third sector also has a key role to play: as significant service provider in localities; as an advocate for carers and service users and; in building resilience in local communities. It would benefit partnerships to draw upon their knowledge and experience and the resources and capacity of the local voluntary sector. However, this should be as an equal partner with third sector representatives included as voting members.

[Question 3 & 4]

Carers Scotland agrees that nationally agreed outcomes should be included within all local Single Outcome agreements and that Health Boards and Local Authorities should be held jointly and equally accountable for delivery. However, we believe that legislation include a power to enable the Scottish Government to revisit this mechanism should it not prove sufficiently robust to achieve the change required.

Carers Scotland believes that the outcomes identified are core to the delivery of integration and, as such, should be written into the legislation. To support future delivery, the legislation should include sufficient powers available to enable the Scottish Government to update outcomes or to require delivery of additional outcomes.

¹² Report of the Commission on the Future Delivery of Public Services (2011)

¹³ Integration of Adult Health and Social Care in Scotland: Consultation – A shared statement from third sector organisations (July 2012)

Furthermore, the legislation would be strengthened by the inclusion of guiding principles for integration. Carers Scotland are in agreement with the “Shared Statement of Adult Health and Social Care”¹⁴ that these should be set out on the face of the bill and should be *based on equality and human rights*, with a legal duty placed on Health and Social Care Partnerships to have due regard to human rights. These principles should also link to the principles set out in other Scottish Parliamentary legislation including the Adults with Incapacity (Scotland) Act 2000, Regulation of Care (Scotland) Act 2001, the Social Care (Self Directed Support) Scotland Bill and in the Patients Rights (Scotland) Act 2011.

[Question 6]

Carers Scotland is unsure about the merits of allowing scope to establish a Health and Social Care Partnership that covers more than one local authority. Rather, it may be more sensible to outline arrangements where local Partnerships may work together on particular activities to deliver better outcomes for individuals and their carers across more than one locality, including accountability arrangements.

[Question 9]

We welcome the flexibility proposed to allow health boards and local authorities to choose whether they should include the budgets of other CHP functions. However, this must be on the basis of consideration of what they contribute to the delivery of national outcomes for integration. Where these functions are critical or important, it should not be left to local determination but form part of national guidance.

Carers Scotland also recommends that consideration needs to be given to how best to include a range of national functions and initiatives within health and social care partnerships in a planned way. The Commission for the Future Delivery of Public Services recommended that, to maximise resources, it is essential to utilise “*all available resources from the public, private and third sectors, individuals, groups and communities*”.¹⁵ In integrating only certain functions, we are concerned that other key initiatives that support improved, or prevent poor, outcomes, may not be included in a consistent way. We mentioned the role of special health boards earlier in this response but other functions include the delivery of national strategic

¹⁴ Integration of Adult Health and Social Care in Scotland: Consultation – A shared statement from third sector organisations (July 2012)

¹⁵ Report of the Commission on the Future Delivery of Public Services (2011)

plans such as telehealth and telecare, end of life care, support for people with dementia and their carers, and wheelchair services.

Furthermore, Carers Scotland shares the concerns outlined in “Shared Statement of Adult Health and Social Care”¹⁶ that the proposals do not provide a clear picture of how integration will fit with self directed support. Nor is it clear how the principles of self directed support will be embedded into the integration of health and social care. As discussed earlier in this response, we believe that legislation should include guiding principles, including enshrining the core principles of self directed support – that people have choice and control over the support they receive (be this health or social care support).

[Question 12-14]

Carers Scotland agrees that Ministers should provide direction on minimum categories of spend that must be included in an integrated budget and, as discussed earlier in this response, consider appropriate levels of housing and associated services spending within this. This could achieve some consistency in approach across Scotland whilst allowing for local discretion to invest additional resources and functions to respond to local needs. Moreover, it is essential that where a “host” arrangement is put in place that there is a clear and shared vision and responsibility beyond that of the joint accountable officer and host organisation.

[Question 15]

Carers Scotland believes that locality planning would be enhanced by the provision of clear direction from the Scottish Government through statutory guidance. This will assist in providing consistency in the delivery and to provide clarity on the level of delegated authority and budgets. This guidance would provide an opportunity to share good practice gained through the work of Community Health Partnerships including the resolution of any difficulties that arose.

¹⁶ Integration of Adult Health and Social Care in Scotland: Consultation – A shared statement from third sector organisations (July 2012)

[Question 16 & 17]

We welcome the proposed duty to consult local professionals including GPs and the third sector on how best to put in place local arrangements for planning service provision.

However, this duty could be enhanced by extending this duty beyond consulting to ensuring that they *actively involve* professionals at the earliest stage. However, whilst the proposals recognise workload issues for GPs, equally third sector organisations require resourcing and support to participate effectively in locality planning.

Draft national outcomes

Carers Scotland agrees with much of the draft national outcomes. However, as outlined earlier, the outcome proposed for carers would be enhanced by expanding this to include carers' ability to have a life outside of caring. We therefore suggest that the outcome for carers is strengthened to read:

▪ **4. Carers are supported**

People who provide unpaid care to others are supported and able to maintain their health, wellbeing and a life outside of caring including paid employment, education, social and leisure activities.

As considered earlier in this response, we also suggest that proposals should strengthen outcomes for older and disabled people and people with long term conditions and include an equality and human rights based approach. This includes incorporating key principles for example:

- personalisation and self directed support,
- the Convention on the Rights of Persons with Disabilities¹⁷ including the right to “*full and effective participation and inclusion in society*”, and
- Article 6 of the European Charter of Rights and Responsibilities for Older People¹⁸ providing older people with the right to “*continued communication, participation in society and cultural activity*”.

¹⁷ Convention of the Rights of Persons with Disabilities, <http://www.un.org/disabilities/default.asp?id=259>

¹⁸ European Charter Of The Rights And Responsibilities Of Older People In Need Of Long-Term Care And Assistance http://www.age-platform.eu/images/stories/Final_European_Charter.pdf

We therefore suggest the national outcome for independent living is strengthened to read:

- **2. Independent living**

People with disabilities, long term conditions or who become frail are able to live as safely and independently as possible in the community, have control over their care and support and are encouraged and supported to live full lives as part of their communities including work, social and leisure activities, education and lifelong learning.

Conclusion

In conclusion, Carers Scotland welcomes proposals for integration of health and social care. It represents a significant opportunity to maximise resources to deliver better outcomes for individuals and their carers. However, as outlined in our response, the proposals would be enhanced by harnessing the knowledge and experience of carers, people who use services and third sector organisations and by ensuring that relevant functions and initiatives are considered as part of vital elements of integration.

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27 August 2012

About Carers Scotland

Carers Scotland is a charity set up to support people who care for an elderly relative, a sick friend or a disabled family member. We are part of Carers UK.

Carers Scotland:

- campaigns for the changes that make a real difference to carers' lives.
- provides information and advice to carers about their rights and how to get support
- mobilise carers and supporters to influence decision-makers at local and national levels
- gather hard evidence about what needs to change and disseminating this to policymakers and services providers
- aims to transform the understanding of caring so that carers are valued and not discriminated against
- provides training for staff in health, social care, voluntary and private sectors
- promotes training for carers to maximise their skills and experience

Most of us will look after an elderly relative, sick partner or a disabled family member. Caring is part of life but without the right support the personal costs of caring can be high. When caring affects carers and their families Carers Scotland is here to provide the support and advice they need.

We help carers:

- get the best for the person they care for
- make the most of their income
- stay in paid work
- juggle their busy lives
- keep healthy
- find a listening ear
- campaign for change.

CARERS Scotland
the voice of carers

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