CONSULTATION QUESTIONS

A Response on behalf of members of the Highland Carer Strategy Development and Implementation Group

The Carer's Assessment: Carer's Support Plan

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

Yes

We support the thinking behind the proposal to change the name of carers' assessments to Carer's Support Plans. We believe that this more accurately reflects their purpose, which should be of determining what support the carer is able to maintain to manage their caring role and have a life outside caring.

But we would recommend that you go further and insert the word 'action' so it reads 'Carer's Support and Action Plan'. We think this will reinforce the idea that the plan is not as a passive document but one that requires the agreed outcome-focussed actions to be implemented for it to be effective.

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

Yes

We welcome this proposal because it would remove a significant barrier to accessing support. It paves the way for carers to access information and support at an earlier stage, preventing crisis and greater cost at a later stage.

However, it is vital to ensure that local authorities and local carer and other community support services to which carers are signposted are sufficiently resourced to respond. We believe that such resources would be a sound investment, as early identification and support of carers will prevent crisis and greater cost at a later stage.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

Yes

This will assist in enabling support to carers in at least three ways:

- as a preventative measure where caring situations are known to be destined to become more demanding;
- when the cared-for person does not want to obtain support for him/herself;

 where there has been a delay in assessing the person for whom care is provided (this could be a factor where the carer lives in a different local authority area from the person for whom they care).

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Yes

This dual approach will be necessary to ensure carers learn about the support available to them. We believe though that to maximise coverage this duty should be extended to acute NHS services and to new integrated primary health and social care services.

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

Yes

This is another barrier which needs dismantling to enable carers to access the support they require.

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

A person-centred approach to the development of Plans will of course, emphasise the need for a timely, appropriate response to the request by carers for Plans. It is not only the Plan itself which will need to be person-centred but the processes involved in all stages of its development - ranging from the offer through to implementation and review. So there ought not to be one standard time for all carers in a local authority area for the time given as to when a Plan will be developed will depend on the personal circumstances of carers.

We believe there's also a need to avoid falling into the trap of seeing carers as being in one of two bald states: either having a Plan or not having a Plan. It is important that the legislation and accompanying guidance encourages, where appropriate, carers and local authorities (and voluntary organisations and Health Boards) to see the creation of Plans over a period of time as being better than being left with no support at all. It is likely that the development of a rapidly constructed, partial Plan (that, for example, signposts people to services that may help them) will be better than nothing at all. While completion of the planning process is also vital, the scale of the task should not prevent making a beginning.

One way of looking at this would be for local authorities (and voluntary organisations and Health Boards) to be encouraged to open Plans rapidly - normally on first contact – and to work from that starting point with each carer to agree how soon her/his Plan is likely to be completed.

Question 7: How significant an issue is portability of assessment for service users and carers?

It is likely to be an issue of growing significance given the aging of the population and the fact that there will be fewer family members (given the smaller size of families and the distance people live from one another) available to provide care. This is likely to increase the amount of caring people do and also necessitate more movement of carers and those for whom they care. In these circumstances it is imperative that the portability of assessments is made as straightforward as possible.

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

Yes

We suggest that carers and carer representatives be involved in all stages of any such process.

Information and Advice

Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

Yes

The key is to provide a service which is effective in its operation – one which reaches to all sections of all the communities served. For this to work the duty will need to be one that majors on the provision of high quality outreach services that actively seek out carers.

Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

It is critical that we don't lose any of the advances made in recent years through the development and implementation of these Strategies so any repeal should only take place if there are cast-iron guarantees about the continuing development of <u>locally-based</u>, highly accessible information services for carers.

Support to Carers (other than information and advice)

Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

We agree that a duty to support carers should be introduced. In regard to an eligibility framework there is a need to exercise great care in this area especially when we consider the principle that carers are to be seen as equal partners in the provision of care. Sitting alongside carers in this partnership are professionals who rightly, are provided with many forms of support in carrying out their work. These supports are far from unlimited but they are significantly more than those available to carers. Amongst the evident dangers here are the following:

- the 'substantial and regular' test is effectively reintroduced via the eligibility framework and two (or more) classes of Support Plans come into being;
- carers are left competing with one another (perhaps even pitted one against another directly) for a share of very limited resources and this leads to illfeeling and a sense of inequity;
- carers are unlikely to feel that they are equal partners with those professional charged with assessing how the eligibility framework applies to them.

Ideally carers should be in a position to determine their own support needs and how these are to be secured – albeit that this process would be well informed by discussions with those who are assisting them in developing and agreeing their personal Carer Support (and Action) Plan

However, if an eligibility framework is to be devised it will be essential that it be seen to be as, far is possible, just and equitable and fully supportive of the human rights of carers. Carers and carer representatives will need to take the lead in the development of any framework which should not be set in stone but subject to regular review and up-date in the light of experience.

Question 12: Alternatively, should we retain the existing discretionary power to support carers and young carers?

No

This discretionary power has not worked as intended as is evident from the unevenness of the support for carers throughout Scotland. The Minister is quite right to see the need to accelerate the pace of change. Effective legislation and guidance can produce a significant step change in the support provided to carers.

Question 13: Should we introduce a duty to provide short breaks?

Yes

Short breaks are a vital, even indispensable, source of support for a significant number of carers to enable them to sustain their caring roles. Enshrining recognition of this fact in legislation would send an important signal to carers in need of such breaks that their role is valued and their need is recognised. It would also mean that the enhancing of the status of carers in the move to be treated as equal partners in the provision of care.

Stages and Transitions

Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

Yes

Ideally over time the need for this should fade but for the time being it is probably necessary to ensure that the changes carers face in the provision of care are properly recognised and appropriate support offered according to these altered circumstances. It is good to see the end of caring recognised within the consultation document as a crucial stage. This is often a difficult time for carers and it is critical for their health and well-being that appropriate support is available for those who require it.

Question 15: Should new carers' legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

Yes

We know of some young carers who have turned into adult carers and this has not been acknowledged, even at times when the young person is the sole carer to a parent.

So it makes a lot of sense to us to think ahead and offer CSPs before the young carer turns 18, with the view to implement it when the YC is 18. This would certainly stop people slipping through the net and would prepare YCs for transition to adult services. Note that young people make some decisions around their futures in Secondary 3 where they choose subjects and start to have a look at what they would like to do in the future and university etc. We think this time would be a good time to look at the start of that process of transition.

Any difficulties that might arise when the young person is not the sole carer – and where there may be another adult in the house who is the main carer – could be handled within the context of a family support plan which would be a good option to have.

Carer Involvement

Question 16: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Yes

Carer involvement - if supported effectively – will enhance the quality of these services. Some attention will need to be paid to defining involvement so that it is not confined to bare consultation but is seen and experienced by carers as meaningful and sustained involvement.

Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

Yes

The arguments in response to Q16 above also apply here.

Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

Yes

Establishing involvement as a principle is desirable as long as this is couched in terms enabling carers to be seen as equal partners in care and therefore that their contributions in planning ought not to be seen as tokenistic but as meaningful. We recognise the issue of consent can potentially be problematic. If consent is withheld in whole or in part close attention will require to be given to support for the carer or young carer particularly when a carer or young carer is still expected by the cared-for person (and is still willing) to provide care.

Question 19: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

Making provision for involvement of young carers in planning, shaping and delivering services is vital. This is how we ensure that our services really meet the needs of those they are provided for. Involvement is also a key tool in the concept of Equal partners in care and the personalisation agenda. If we are equal partners we would assume that means "equal" and that involves people in all aspects. It is also very empowering for young people to have a voice, to feel heard, to engage and contribute to something tangible and to feel that their opinion and experiences are valued. In addition, improving things for future service users can be a powerful driver for people and give them a sense of achievement and of change being possible. We cannot empower young people by excluding them, we must involve them, engage them, listen to them and grant them enough respect to them use their input to make things better. Involvement should form a large part of any planned project and this should be costed into planning at an early stage.

Planning and Delivery

Question 20: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers' strategies which must be kept under review and updated every three years?

Yes

High quality, effective and dynamic strategies will enable

- an evaluation of practices and policies pursed;
- an assessment of changing patterns of care;
- an analysis of trends regarding the types of support being requested by carers;
- clarity as to carers' desired outcomes and how these are to be achieved.

Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Yes

Without this happening it is likely that in practice services provided will vary in unacceptable ways. The key phrase above is 'a sufficient range of services'. Ultimately it is carers collectively who will be determining whether that range if sufficient to supporting them in achieving their desired outcomes. This makes it imperative that carers are at the heart of the shaping of the services that are designed to support them.

Identification

Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

We believe that there should be a legislative requirement for GP practices to develop a register of carers within their practice and that this register be labelled the Carers Action Register to signal that it is not intended as a data collection exercise but as a means towards the end of providing tangible support to carers (e.g. referring carers for Carer Support Plans, periodic health checks etc).

Question 23: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

Yes

The key word in this question is 'ensure'. For Health Boards to 'ensure' the widespread dissemination of good practice they will need to evidence not only that information has been shared but also that the good practice is being implemented. Too much sharing has in the past been limited only to disseminating the knowledge and has not encompassed the resourcing of the implementation.

Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

Yes

We agree that GPs should be required to report annually to their respective Health Boards on compliance with the GP contract. We also agree that Health Boards should, in turn, be required to report on compliance to the Scottish Government. Reporting should include: the number of carers identified within the practice; how many carers have been referred for an assessment; and how many carers have been given additional support. To provide a focus for carer identification and support, we believe the appointment of a carers' lead within individual practices would be beneficial.

Carer and Cared-for Person(s) in Different Local Authority Areas

Question 25: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

Ideally the carer should have the choice of deciding which local authority should assist her/him in the undertaking of the Support (and Action) Plan since there are arguments in favour both ways.

Question 26: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?

In responding to this question we are assuming that carers can have the choice of selecting the local authority that should work with him/her in producing the Support (and Action) Plan and in that case the chosen local authority should then cover the cost of support to the carer.

Question 27: Should the Scottish Government with COSLA produce guidance for local authorities?

Yes

This should also be done in partnership with carers and representatives of carer organisations.