

## CONSULTATION QUESTIONS

### 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

No

Comments: Yes, because the word 'assessment' is too much like an exam or test to see if you are fit to care for your own family – rather like 'parenting assessment' as used in Child Protection cases

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

Yes

No

Comments: All carers should be eligible

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

No

Comments: As therapeutic and practical help for my son from the NHS and from the Local Authority is now restricted to crisis cases many people like me get no help yet provide hours of ongoing care – I actually need more support as a carer rather than less due to getting no help from the services and providing the care myself to him.

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

No

Comments: The NHS and GPs should also have the ability to trigger a Carer Support Plan – most new cases where families need help originate with health problems anyway

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

Yes

No

Comments: See question 1. Also it is disrespectful to carers and does not reflect their proper role as partners which I thought was part of the NHS and Community Care Act anyway

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?

Yes

No

Comments: I kept getting promised support but in 16 years have only had 2 'assessments'- one on my son's diagnosis and one when he was 18 to 'discharge' us – even though he had ongoing needs- we were told to contact adult social work ourselves if 'things got out of control' = that is not preventative care

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

Comments: Very important. We feel we cannot move house in case we have to start again asking for help

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

Yes

No

Comments:

### 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

No

Comments: This is vital – carers need to get quality information from the start and the requirement in the NHS and Community Care Act to inform carers of their local carer support services has been ignored - NHS staff , especially in hospitals, are so unaware of the need for carer information – they just want to discharge the patient asap. Carers centres are essential for more than information- they build up a therapeutic relationship with the carer over years- in my case 10 years! They are with you on your journey through caring. They could not be replaced by a call centre or leaflet pack- carers need specific and local information which is credible, not an out of date leaflet like you see in hospitals.

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?

Yes

No

Comments: The NHS as well as Local Authorities should have the responsibility of having a Strategy and funding these carer services, otherwise it will get lost in the need for other NHS spending. This is the case despite the planned Integration of health and community care services as I think this integration can be watered down locally and become only a bureaucratic exercise

### 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?

Yes

No

Comments: Unless Local authorities have a DUTY to provide services then this legislation is pointless and has no teeth. It would leave us in the same situation where carer services are seen as optional by the council and NHS and thus liable to withdrawal when budgets are tight. The eligibility criteria should be consulted on locally but there should also be some national minimum standards otherwise we go back to a postcode lottery.

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

Yes

No

Comments: See Question 11

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

Yes

No

Comments: See Question 11 - also Short breaks should not just be confined to respite care when the cared for person is admitted somewhere for a week or so, but should also include breaks of 2-3 hours on a weekly basis, to allow the carer to go to a club, class, gym, meet a friend etc. That would be truly a preventative service as the caring journey, especially for parents of a disabled child, is many long and weary years. You have to try to keep well and healthy as your child has NO-ONE else to care for them - society and the state effectively gave up this responsibility with the Community Care Act which gave the whole role over to families without developing adequate services as a right – you are made to feel like a benefit scrounger for any government help.

## 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

No

Comments: Yes – the needs for support when you first hear of the diagnosis is different from later – at first your entire concern and focus is on the medical

condition and needs of the cared for person and not on yourself. It is only later you realise the impact on yourself and the rest of the children in the family. Staff need education in the stages of caring journey and different families responses. There is a difference, but equally valid in , in a carer's needs when there is a gradually increase in the cared for person's needs (e.g. dementia) and the sudden falling off a cliff edge when your child has a disability or your husband has a stroke.

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

No

Comments: Young Carers do not get enough focus in these proposals, including siblings of children with special needs. Disappointingly Young Carers do not get enough focus EITHER in the new Children and Young People's Bill/Act just gone through the Scottish Parliament. ALL young carers should have a Support Plan , not just those who are exhibiting obvious impact – that is not preventative at all. Young Carers' needs get left behind in Children's Services because the focus is all on Child Protection now, yet the assumption in carers services is that their needs will be met within children services. They are falling between 2 stones. Whenever I asked for help for my daughter who was affected by the needs of my disabled son I was told that the priority was for child protection families. I was able to fight for some help years ago when my children were small, but now I now families like ours who get no help at all . THIS IS SHORT SIGHTED.

## 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

No

Comments: This should be a core principal in the new Bill- professionals are planning local services and they all sound good but they have not got experience of being a carer and how even a small amount of the right help at the right time makes a huge difference in the long term.

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

No

Comments: Carers centres and organisations are the only voice that carers have and the only way to influence planning. However carers need support to input into planning – expenses to come to meetings with the council etc, getting onto

broadband etc

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

No

Comments: The biggest impact on long term carer health is the quality and quantity of services the cared for person gets. It is hugely stressful having to see an inadequate, poor, unkind or impersonal service supposedly providing 'care' to your relative. It is actually easier and less stressful in that situation to it by yourself without NHS or Council staff help, even though in the long term it is damaging on your back and mental health. I think more questions should be asked of the NHS about why so many changes to the way they deliver therapeutic and rehabilitation services have been made without public consultation or indeed any clinical effectiveness evidence. For example a 10 week 'input' from a Speech and Language Therapist with a few leaflets at the end is no help at all in the life of a child with a disability. Yet there are many examples of excellent outcomes after long term therapy. The interventions nowadays in many clinical therapies come too late and are too short to be of any effect.

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?

Comments: Young carers can be articulate and full of great contributions when asked – look at the Young Carers Parliament. If they can vote now at 16 then they should play a full part in planning services.

## 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

No

Comments: This seems obvious if we are going to get local services which meet carers needs and not the needs of the organisations.

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

No

Comments: Again this seems obvious if we are going to get local services which meet carers needs and not the needs of the organisations.

## 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?

Yes

No

Comments: I DISAGREE with this proposal for no legislation. GPs respond best to legislative imperatives, not just best practice. However the Register should be used proactively to plan for individual carers health needs and prevent problems for the future – obviously with the carer’s consent. For example as well as being contacted to be offered an annual flu immunisation and Health and Well being check by the doctor or nurse (not an untrained staff member or even volunteer as I have heard happens) the GP computer system should be configured so that as soon as the carers medical record is opened it flags up that the person is a carer. This way the GP and practice nurse might actually connect the presenting symptoms (back pain/sleep problems/migraine/stress/low mood/depression/weight and eating problems etc) with the caring role. This system should extend to the Emergency Care Summary which is available to NHS 24, Scottish Ambulance Service and A&E Depts. Carers often unwillingly delay getting help for illness at their GPs due to inflexible appointment times or lack of someone to take over their caring role to let them get to the surgery. I know how dependent they are on Out Of Hours Health services when these illness become urgent- they need treated sympathetically by the staff of the above organisations and not treated as time wasters .Monitoring should take place in these organisations of how many carers they identify and direct to sources of carer support (this is already law in the NHS generally but rarely happens) and results should be published – it is well known that *if a process isn’t measured it isn’t valued, therefore it doesn’t happen in the NHS.*

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

No

Comments: Yes, but only if backed up by legislation – it is not enough to only exhort GP to undertake good practice – as above – *if a process isn’t measured it isn’t valued, therefore it doesn’t happen in the NHS!*

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

Yes

No

Comments: Absolutely – I can't believe this doesn't happen already

### **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)?

Comments: Carers should be able to access services either in the LA they live in or which the person they care for lives in. Different solutions will suit different family situations. However this is not an excuse for LA to 'pass the buck'

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

Comments: As above – an agreement should be reached between the two local authorities but it should be the one where the carer pays Council Tax.

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

Yes

No

Comments: