

## 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

We support the change of wording from 'assessment' to 'support'. PAMIS feels that the term support is a more positive term and it is in line with the terminology used when promoting the Self-Directed Support (SDS) approach to care. PAMIS supports families caring for people with profound and multiple learning disabilities (PMLD) and therefore these families level of caring is substantial. The level of caring required often makes it difficult for the carer's 'aspirations' or 'needs' to be recognised over and above the needs of the person they care for. A support plan which focuses on outcomes for carers is a positive step and will encourage carers to focus on their own personal aspirations.

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

PAMIS agrees with the removal of eligibility criteria. Some of the families that PAMIS support have sons or daughters living in supported accommodation, the removal of the term 'substantial' and 'regular' will allow these carers to receive a carer's support plan. These families are still on call 24/7, especially when they are welfare guardians of their sons and daughters, and provide essential caring tasks and a training role free of charge for staff working with their daughters/sons. This recommendation will allow their caring role to be recognised. However, the removal of an eligibility criteria will have significant council resource implications and this must be recognised appropriately.

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

The carer's assessment should be open to everyone that provides a caring role. In some cases the cared for person may refuse help from the local authority and in these cases it is important that the carer should not be excluded from the right to an assessment. In some cases when a carer is so successful in providing care it can result in little or no service provision being necessary. It is therefore conceivable that some

family carers are overlooked. This is especially so for parents who are caring for children, as some parents may not view themselves as 'carers'.

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

It is important that the route through to getting an assessment 'support plan' is made as accessible as possible with no barriers. It is also critical that the necessary information is available so everyone is aware of the existence of the Carer's Support Plan.

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

Yes

No

The term 'ability' is not in line with 'support' and has negative connotations.

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

Carers should be made aware from the start the length of time that the process will take. Timescales are really important to families. Carers are under a lot of emotional pressure in their caring role and it is important that they don't feel let down and abandoned by the system or have to spend time chasing up their support plan. If carers are told from the outset the time it will take to receive their Carer's Support Plan they will have realistic expectations and reduce stress. Additionally, It will make sure that local authorities are accountable and have a timescale that must be adhered to. This is in keeping with the Self Directed Support approach to coproduction and respect.

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

It is important to remove barriers. It is entirely possible, for a variety of reasons, that a service user and carer may move to another local authority, continuity of support is important. The portability of individual health documents such as Individual Care Pathways for people with PMLD is crucial especially when they are admitted to an acute hospital setting as it means that staff have immediate access to crucial information. In line with patient centred policies and procedures and partnership working with family carers there are huge benefits to having portability of assessments.

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

Yes

No

The Scottish Government and COSLA should work together to improved consistency of services and support across local authority boundaries.

### 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

Good quality, timely, information and advice are crucial to supporting carers. This information should be made available in the relevant formats to meet differing needs.

There are a number of third sector organisations already set up to provide this service - generic carer organisations as well as specialist organisations such as PAMIS that have the expertise in supporting carers looking after a person with profound and multiple learning disabilities.

The same ethos of providing information and advice with signposting to relevant organisations if necessary as is promoted under the SDS approach should be in place in regard to supporting carers. It is counterproductive to ignore carers who are after all supposed to be partners in the overall caring experience.

Good quality Information, Advice and Support is the key to successful engagement with carers. Improved knowledge, information and advice of The Carers Support Plan will enable better engagement with the processes and quality information is key to achieving this outcome.

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

The role of Health Boards has been crucial in developing carer support and the repeal of section 12 of the Community Care and Health (Scotland) Act should only be undertaken when the Integration for Health and Social Care is well established and consideration is given as to how the Scottish Government are going to provide future funding that will enable the continuation of the valuable work that is currently undertaken by Health Boards.

## 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

Yes it should be a duty as this will help direct support to carers who need it most for whatever reason. It should however be stressed that any eligibility framework developed should be inclusive, fair and designed to enable all carers to access support as required. It should also allow for a regular review of circumstances as carers needs may change over time.

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

Yes

No

History dictates that having the discretion to provide support can make it easier for local authorities to opt out of providing support. There needs to be consistency across the board to ensure a postcode lottery effect is removed.

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

Yes

No

As all carers benefit from time away from the caring role it would seem that provision of short breaks is warranted. It is also necessary to enable carers to continue to carry out care and to maintain their own feeling of wellbeing. Knowing that a break is on the horizon is so helpful. Having a short break apart is also beneficial for the cared for person too.

In regard to PAMIS families who are looking after people with complex health care needs provision of short breaks/respite must integrate well with *The Public Bodies (Joint Working) (Scotland) Act 2014* which will hopefully, once implemented, affect families caring for a person with PMLD and complex healthcare needs positively and resolve health care issues when accessing self-directed support such as short breaks.

## 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

Yes, as there are different levels of care provided depending on the levels of care required. In regard to family carers caring for a relative with profound and multiple learning disabilities (PMLD) and complex medical healthcare needs the level of care required is intensive and consistent. This would of course be different for other carers whose care role was directly related to caring for a person who had a condition that either fluctuated or where a person's condition became progressively worse. Any guidance should reflect the needs of carers such as those who care for a person with PMLD who provide intensive and consistent care. Guidance for this particular group should look different as their caring roles require the investment of not only time, but also emotional and physical input. Transition from services is notoriously difficult for family carers and everyone within the family unit. Extra support during times of transition is necessary for everyone involved, including siblings.

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

Yes, this would make sense as support for the person with disabilities and those caring for them is necessary. Family carers do not carry out care in isolation. Young people must have consistent support when transitioning from children's carer support services to adult carer support services. Planning is key and enables carers to move through, what can be an emotional and difficult time successfully.

## **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

Absolutely as in line with Equal Partnerships in Care and within the ethos of SDS people in receipt of services or in the case of people with PMLD their carers should be included in partnership working in providing care and their input into any initiatives involved in planning and shaping of service delivery should be sought and listened to. Carer involvement in planning, shaping and delivering services will ensure the quality and relevance of the service delivered is actually what is required. Carers can also advise on what training requirements are necessary to deliver a service that meets the needs of people using the service. Additionally, given the huge amount of money saved by the government because

of the continued hard work of family carers it can only help good relations from both sides if they are involved and listened to from early on.

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

Yes. PAMIS is an organisation that supports family carers who care for a person with PMLD. PAMIS can collectively advocate for this particular group of carers and will do so with these carers best interest and that of the people they care for in mind. Organisations that support specific groups will have a wealth of information relevant to provision of care services being proposed for future use. Not tapping into this rich source would be unhelpful in the long term. The expertise and knowledge of carers organisations in terms of the provision of information, advice and training is invaluable.

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

Yes especially in respect to the values and principals of the SDS approach to care e.g. personalisation and coproduction. The core values of personalisation i.e. inclusion, equality, fairness, freedom, and safety are appropriate regardless of whether legislation is in place and should exist for both the person being cared for and the person, regardless of age, providing that care. Again, the principles of Equal Partners in Care highlight the benefits of the expertise and knowledge that carers bring to any care planning for the people they support.

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?

Where able and appropriate, young carers should be involved in planning, shaping and delivering of services. Young carers are on the front line and their knowledge and understanding of what services and the way services are delivered mean for the person they care for, and themselves as carers, should be acknowledged. Their insight into what would better support them and the person they care for should be useful and listened to. A carer needs to feel that they have a voice and are listened to regardless of their age.

## 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

Yes, the involvement of grassroots carer strategies is necessary as they can feed back to relevant groups as to how initiatives, policies and procedures are working in the community. These local groups also enable carers and carer support groups to voice concerns and have these concerns addressed. Carers and the organisations that provide support to them have the knowledge and expertise that would enable them to make a valuable contribution to the development of policy and strategies.

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

Carers who require extra support must be able to gain information on whom and where they can access the necessary support. If it is part of the strategy to improve the wellbeing of carers and stipulated in legislation that integrated health and social care services must support carers in this way, it will alert organisations or individuals capable of offering such support of the gap in the market. The outcome will hopefully result in the development of services that will address this gap

### 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

There should be legislative requirement for GP's and local authorities to maintain a carer's register in order to support the identification of carers. Following identification carers should then be signposted to relevant information and support services.

The integration of Health and Social Care should enable registers from both GP's and local authorities to be shared on a common database

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

We don't think that 'good practice' is sufficient, there should be a duty for GP's and local authorities to actively ask people if they have a caring role and maintain a register.

It also is necessary for primary and secondary health services to have systems in place where they can share information on carer identification. It should also be a duty to inform and involve carers in hospital discharge procedures.

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

Yes

No

Health Boards should actively monitor the core contractual elements of the GP contract. The core contractual element should also be extended to include a register of carers with a lead person in each GP practice to be responsible for signposting carers to any information, advice and support organisations. Each Health Board should also have a carers Support team that raise awareness about carers in GP practices.

### **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)?

It makes more sense for the assessment to be carried out by the local authority that is actually carrying out the assessment of the person being cared for. Where a carer lives in a different local authority then both authorities involved should have procedures and policies in place which will enable them to carry out fair and equitable responsibility regarding the cost of any support offered. There also needs to be provision of adequate systems and processes that allow sharing of information between local authorities in these instances.

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

Please see previous comment. Negotiation is necessary between both authorities with equitable splitting of costs on a case by case bases or if at the end of a financial year an averaging of all out of authority costs should be made and each authority take responsibility for a percentage of the cost. Depending on circumstances this may result in no exchange of budgets as they may cancel each other out.

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

Yes

No

It will be helpful to have guidance for local authorities so it is equitable across Scotland.