

PASDA response to Scottish Government Consultation on Proposals for Carers Legislation. We at PASDA have a distinctive role to play for not only do we provide help, assistance and advice to carers of Autism and Aspergers (a group of people distinct from disability sufferers and those with mental health concerns), but as far as we are aware we are the only charity in Scotland providing this important role. This response has been written in conjunction with staff and carer's.

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: A Carer's Support Plan is more friendly and supportive. However, a Carer's Support Plan is still only a plan until it is activated and who will do that? It will be very hard to explain the depth of support that someone with autism requires as it is invisible. We are much more concerned about the actions and outcomes of the plan and an assessment is just that an assessment of need. There is no mechanism mentioned here to address the need. So the need may be assessed but not addressed This means there is very little change if our carer's are told that although they have a need there is no budget to meet this need therefore what changes will be made? LA need to increase resources in anticipation of demand when carers are informed of their Carer Support Plan.

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: Our carers are frustrated that they have a right to a carer's assessment but not to the support and resources they are assessed as needing. Also there is no standard response time for a carer assessment to be completed – this can vary from 4 weeks/12 weeks across Scotland. We welcome the proposal that 'all' carer's will be eligible for the Carer's Support Plan but we need the resources to facilitate this.

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: Cared for individuals do not always require such services therefore removal may allow more carer's access to this support if required.

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: Increasing the accessibility and awareness of possible routes into a carer's support plan is positive.

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

Yes

No

Comments: This can imply a negative view of the carer's competence or skills and as all our Carer's are unpaid this can be demoralising. A carer needs to have their own life recognised alongside their caring responsibilities. Some of our carer's fear that the eligibility criteria will set the bar too high and create a move away from preventative support. However, removing from statute the wording will break down barriers and become more inclusive.

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: We welcome the emphasis on "duty" to inform the carer about the time frame for the assessment. We need no resistance from local government to being honest about the length of time this process will take and if our carer's are made aware of this from the onset then they know what to expect.

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

Comments: This is a large concern to carers during transition and moving on from one LA to another. Files can be lost, misplaced, and this in turn means that the carer's information has to be repeated again and again causing much distress and upset to our already vulnerable carers. This new duty will need to be resourced otherwise LAs may cut budgets elsewhere causing an even harsher impact on resources and availability of services for our carers.

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: There will always be variability of service provision in different local authority areas. However, having a streamlined portability policy will allow carers to feel supported in the transition period. Thus, causing less distress and upset.

Communication and protocols between LA's need to be improved if this is to be successful in implementation. All involved parties need to plan well in advance before the change occurs in order to create a person-centred strategy approach. Not only is planning required before the transition but there needs to be regular reviews to ensure that the transition has been smooth and successful and, if not, a plan has to be implemented to ensure a positive outcome.

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 should include support provided to Carers by the Third sector.

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: We still need to be able to have funding towards the costs of information and advice services provided by SG and this may be cut if this is repealed. The Health Boards are supposed to have a carer information strategy but what happens if this is not replaced? Who ensures it is acted upon?

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: We agree there should be a duty (a legal obligation) to provide all carers with a care support plan. We should support the option to introduce a duty to **support** carers, whilst acknowledging this duty would still need to be linked to an eligibility framework – this framework needs to be national. Need should be outcomes based support planning via conversations with carers. A duty to support carers would herald an approach similar to that used for the people they care for.

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

Yes

No

Comments: This can be useful, particularly for carer's that may be experiencing a crisis. It can also benefit carers to form a preventive basis to ensure that their good health and well-being is maintained.

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

Yes

No

Comments: We think this is correct but who will enact the duty and decide who is eligible? There is unanimous support for a Duty to Support. Carers are tired and frustrated at having to fight for support, feeling guilty at having to ask for help and receive 'hand outs'. Duty should be accompanied by a statement which clearly explains what is available and how one should ask. There is a need for consistency across Scotland. We are aware some carers are entitled to three 11 night breaks each year and in extreme cases this can be extended to five breaks p.a. – partners caring for Parkinson's and dementia suffers, for example. The minimum we should be claiming is 5 day breaks. There is a need to protect all carers, not just those lucky enough to live in a well- resourced area.

The duty to provide short breaks should be linked to a requirement to produce a statement of short breaks availability as this would bring clarity for carers to an otherwise confused situation. This will definitely require more investment if short breaks are to be deemed a duty. Decision making could be devolved to the carer voluntary sector, a more cost effective route and a better option for carers.

Carers stay physically and mentally more capable in their caring role if they have the respite and short breaks they need to maintain their own mental health and well-being. The short breaks should not only be offered in crisis situation but also as a preventative measure. Costs for carers in relation to short breaks are relatively modest. For example, help with gardening, gym membership, buying a laptop (increasingly possession will be seen as a necessity) are low cost interventions to help the carer look after his or her own health. Some types of health will cost more but should help the carer to care for longer in better health and avoid breakdown or crisis. Prevention leads to far fewer breakdown and crisis situations. We feel that carer centres may be best placed to carry out carer support plans as what they do is all based around carer needs. They offer information, advice, support, training, peer support, advocacy, counselling.

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: Most definitely as this is an area of concern for our carers as what will happen to the person they care for when they are no longer here.

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: Support through transition is immensely important.

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: Yes definitely especially the delivery of services but it needs funding to achieve anything. Our concerns are very particular to all the carers who support adults with autism and Asperger's syndrome. All those people fall between disability and mental health problems and their voice needs to be heard.

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: Local carers' strategies should address the issues of need. This is what we should aim for and we agree to this strongly in this consultation. Following on, LA should ensure that there are sufficient services. We completely agree but it is the 'how' that needs to be explained. In the consultation there is a statement that there should be a 'definitive list of universal, free services available to carers'. We do not know what this means. What is free? The service provided by social services? The SG is concerned that there is evenness of distribution throughout Scotland to reduce rivalry but it is impossible. Instead they should aim for the top with high standards everywhere and question those authorities who do not comply.

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: LA's and SG need to listen to the Carer's views and opinions on what they need, after all, they understand the needs of their cared for person better than anyone else. The carer is the expert not the other way around. Although organisations may see more varied requirements the carer will be able to see the bigger picture and will know how their cared for person will benefit most from being supported. This needs to be an integral part of the care planning process. Secondly, we should encourage our families to respond. However, there needs to be guidance on what they are responding to as they need to know a considerable amount of knowledge about Local and Central Gov structure in order to understand the changes.

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: This needs to be integrated and integral to the planning process.

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: Yes, there needs to be a consultation exercise at least every three years to review and maintain appropriately.

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: It is clearly everyone's responsibility to make this information and advice readily available.

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: There should be appropriate provision made available and resourced for GP's and LA's to maintain a carer's register in order to support the identification

of carers.

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: Scottish Government recognises that identification of carers remains a challenge despite a wide range of initiatives designed to improve this. Particular importance is placed on the role of GP practices and how they can identify and refer carers for assessment. The mechanism for this is the GMS contract, the contract between GP practices and NHS Health Scotland. GP practices currently apply a code to an individual's medical record within the practice if they are identified as a carer. Scottish Government has suggested there should be no legislative requirement for GP Practices and local authorities to maintain a Carers' Register **but** that good practice on the use of carers' registers should be proactively shared with Health Boards.

GPs and allied health professionals are perhaps the best placed people to identify carers at any stage in the caring journey as all of us will use GP services throughout our lives. However, identification of carers through GP practices remains inconsistent across Scotland and there is limited evidence to suggest that GPs actively seek to identify carers they come in contact with.

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

Yes

No

Comments: We agree with other Carer charities that there should be a legislative requirement for GP practices to develop a register of carers within their practice. The coding mechanism is already in place to enable a register to be created. However, there is limited value in creating a register if it is simply data collection. We believe that in addition to the identification of carers, GPs should be required to proactively refer carers for assessment and that this should be recorded on the individual patient record.

We also advocate that the carers' register should trigger a review of the individual carer every 6 months to determine if the carer situation has changed and whether additional support is required in terms of the carers own health and wellbeing. This may also have a major impact on hospital discharge planning: We agree with other Carer charities that the forthcoming carers' legislation is an ideal opportunity to embed discharge planning into statute, ensuring that health boards and local authorities plan to coordinate discharge from hospital in a way that is inclusive of carers and the role they play in looking after people following a stay in hospital. We believe that a duty should be introduced on health boards to inform carers and involve them in hospital discharge planning.

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: We feel this should be done jointly as an added complication would be if someone worked/lived in a third LA area and needed support in maintaining their employment.

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: Again should be shared and covered jointly.

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

Yes

No

Comments: We feel that to maintain and produce best practice guidance between all LA and SG this should include Third sector organisations. Our main concern is that there are no clear action points that will actually make a difference to the carer. It is all about a process and a structure. LA may make plans as requested but there is no one to enforce action. There may be policy, lists, strategy and duties but we need a process from the view of accountability and fairness which is not apparent. Our carers need to be able to say what they want not what they don't want. Moreover, they need to be listened to and not simply acknowledged. They need to be a pivotal part of the process not just consulted with their views.