

CONSULTATION QUESTIONS

Carers Trust Scotland, along with other organisations that form the National Carer Organisations, consulted widely with carers and carers' organisations in order to inform this response. Quotes and statistics that appear in this response, unless otherwise attributed, are drawn from this consultation exercise. Full details of the consultation exercises have been submitted as part of the NCO response to the consultation.

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 believe that a change of name to Carer's Support Plan more accurately reflects their purpose, which should be to plan what support can be provided to help carers manage their caring role. The idea of a plan rather than an assessment is more indicative of an ongoing process with regular review, rather than a one-off discussion. Many carers do not like the term Carer's Assessment believing it to be judgmental; a large majority (86%) of respondents to our questionnaire agreed that a change of name was the right approach.

Recent research that was undertaken as part of the development of the Carers Rights Charter¹ found that despite a legislative duty to offer carers assessments, only 38% had been offered an assessment with 18% offered a self-assessment. Of those offered an assessment, only a third had received one. More than half of carers said that their carer's assessment was useful (27%) or partly useful (38%). However, the majority (69%) reported that their assessment led to no new support for their caring role.

As acknowledged in paragraph 2.3 in the consultation paper, a number of carers' centres use the term Carer Support Plan to refer to the plan of support they offer to carers who they work with – it is important that the Carer Support Plan offered by these services remains distinct from the statutory assessment, particularly if it is the carer's centre that is carrying out the statutory Carer's 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

We support the proposals to remove the 'substantial and regular' test so that all carers would be eligible for a Carer's Support Plan. This will mean that carers are able to access support at an earlier stage, preventing crisis and greater cost of support at a later stage. However, it is vital that sources of support for carers, which may experience greater demand for their services if a larger number of carers are signposted to them, are

¹ Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

adequately resourced to provide this support.

This requirement will impact on the proposals in this consultation around information and advice for carers, and is also an important consideration when developing statutory guidance that outlines the role of the third sector in undertaking the Carer's Support Plan. Increasing the uptake will mean greater pressure on the agencies carrying out the Carer's Support Plan, but as there is a clear preference from carers to have the Carer's Support Plan carried out by carers' centres and other third sector services, the third sector needs to be supported to do this. It needs to be clear that the duty still sits with the local authority, and there must be a standard process for picking up on needs identified through the assessment. Best practice indicates this should include identified workers from the local authority who link with the third sector organisation, so that there is consistency and clear 'reporting lines' from both organisations.

"It is important to remove the 'regular and substantial' test and extend Carers Support Plans to all carers. This will mean early identification and should help more carers receive appropriate support. The support plan should be based on carers needs and be regularly updated to ensure that, as young people and carers grow older, plans continue to meet needs. It is essential that carers are given support to have lives outside caring."

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

We support the proposals to separate the carer's assessment from the assessment of the cared-for person, so that a carer can access an assessment even if the person they care for is not in receipt of any services. Many carers are looking after someone who is either not eligible for local authority services or who is not willing to have an assessment of their own needs, but the carer still requires support. However, in many cases, the carer is supported by increased provision of the support for the cared for person, so that the carer can care more easily or in some cases reduce their caring role. This must be taken into consideration.

"It would be wrong to exclude any carer because the person they care for perhaps doesn't want community care or other support. These are perhaps the carers who need support most of all."

"Yes it shouldn't matter that those you care for don't receive any other services. That might be down to choice, the carer may not have been given a choice or local cutbacks will lead to the person being cared for not receiving services. The carer may still have a caring role and may need support."

51% of carers agreed that this provision should be removed.

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

We agree that as well as carers being able to request a Carer's Support Plan, the local authority must offer it. Carers, particularly those who are new to caring, may not be aware of support that they are entitled to, and it is important that agencies inform carers of what is available to them. However, this requirement should be extended to acute NHS services and integrated health and social care services.

It is also important to ensure that if the carer is requesting a Carer Support Plan, they are able to make their own judgment on whether a 'light' or 'full' assessment is required.

This is supported by carers with whom we consulted, with 99% being in favour of this approach.

"If it is not a duty, it won't happen."

"It is important to remove the 'regular and substantial' test and extend Carers Support Plans to all carers. This will mean early identification and should help more carers receive appropriate support. The support plan should be based on carers needs and be regularly updated to ensure that, as young people and carers grow older, plans continue to meet needs. It is essential that carers are given support to have lives outside caring."

We believe that this will enable carers to access the information and support they need earlier, preventing greater cost at a later stage. However, it is vital to ensure that in responding to increased take up, local authority and local carer and community supports are sufficiently resourced.

"Monies given to local authorities should be ring-fenced for the Carers Support Plan."

"Prevention must remain at the heart of Carer Support Plans and eligibility criteria must reflect that so councils do not default to crisis only intervention or set the eligibility criteria so high that only carers in desperate situations get a Support Plan completed."

We agree that statutory guidance should underpin the depth of Carer's Support Plans but that the scope should be informed, in all cases, by the needs and wishes of the carer. The majority of carers (85%) with whom we consulted also agreed that statutory guidance was required and with the proposal to have different levels/depths of Carer Support Plans (89%).

"All carers should have the same opportunity to identify areas where support may be needed. If a lower level is used the carers may not be aware of all the support which may be suitable/available."

"Each carer's role is different, with different needs and help required. The support plan should meet the needs of the carer and the cared-for person and should be unique to their needs."

"Yes because things vary and it also depends on the context of the carer's other commitments."

We also agree that statutory guidance should be in place to describe what should be included in discussions for the Carer's Support Plan, particularly a carer's right to choose the level of care (if any) they are willing to provide and their right to a life outside caring. Research shows that very few carers know that they could decide what level of care they were willing and able to provide or that they are able to make choices about their caring role. We would also recommend that the Carer's Support Plan should incorporate emergency and anticipatory care planning.

We have some concerns at the proposal not to legislate for a minimum set of issues to be discussed as part of a Carer's Support Plan. We believe that this may result in inconsistency. In our consultations with carers, 96% said that the Scottish Government should legislate to provide a minimum standard for issues to be discussed.

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

Yes

No

In our consultations with carers, the majority (96%) agreed with the provisions to remove the reference to a carer's ability to care.

"We should be aware of the carer's capability to undertake caring tasks rather than judge their ability for tasks. However, training should be provided where tasks require training for professionals."

Clarification is needed on what 'ability to care' actually means. If not removed, it should be reworded to clarify that 'ability' includes willingness and capacity to provide care as well as competency and skill.

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

Whilst in favour of this in principle, we think this would leave too much of an opportunity for local authorities to set their own standards and there would be unequal provision across Scotland. Whilst it may be beneficial for the carer to know how long it will take to receive a Carer's Support Plan, this will not solve the current situation where carers can wait for many years or months to receive a carer's assessment.

"Been trying to get help for 15 months. There should be a published process which is consistent. This should also have a timeframe in which this must be done."

We recognise the challenges in setting maximum waiting times, but believe there should be a defined timescale for a Carer's Support Plan that should reflect both the time for local authorities to undertake an assessment and also to provide services that carers are eligible for. This timescale should not be more than twelve weeks. This is to ensure that carers do not reach crisis point before they receive support. Local authorities should

consider contracting carers' centres to carry out Carer's Support Plans in a particular area if they cannot complete them in a reasonable time period.

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

Portability of assessment is a significant issue for some carers and their families, but the main issue to be resolved is around the portability of service packages (and funding) rather than the assessment itself. Whilst we recognise that local authorities' service provision differs due to the needs of a specific area and population, the different thresholds at which people may be eligible for support from one area will impact on the continuity of a service if people move areas. Our response to questions 23-25 are related to this question.

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

Yes

No

When a carer lives in a different local authority area than the person they provide care for, a number of issues may arise which require clarification and this may become more of an issue in the future, subject to legislative change (the proposed duties on local authorities to carry out carer support plans and provide support to carers.) It is likely that 'caring at a distance' will increase in the future due to changing family structures and migration patterns. In addition to providing care, families may have to contend with long journeys and the additional emotional strain on not being 'on hand' should an emergency arise. The Scottish Government and COSLA need to work together to ensure that all carers in Scotland are treated fairly and equitably, and provided with suitable support, if they move to a different local authority area.

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

We agree that local authorities should ensure that information and advice about the Carer's Support Plan (and for support to carers and young carers) is provided, and therefore support the proposal to place a duty on local authorities to establish and maintain an information service. However we have concerns that local authorities may try

to establish their own services in order to reduce costs rather than resourcing and supporting existing carers' services. Carers' centres and services have a very important role in supporting carers, and whilst this proposed duty includes a requirement that information should be provided about support to carers provided by third sector organisations, we believe that this does not go far enough towards recognising this important role. As most areas in Scotland have a carers' centre or carers' service, these services should be supported to continue their work as they have already established a local presence.

Carers who responded to the online questionnaire and participated in consultation events are completely in favour of the proposal to place a duty on local authorities regarding information and advice provided to carers, provided that carers' centres and services were not overlooked.

"They should have a duty to inform re services available such as respite, community care, benefits. They should have a duty to ensure that a good quality service exists."

"Use the existing services as a starting point."

Many carers were not in favour of a local authority operating its own in-house carer support service; sometimes this was due to bad experiences with social work or other local authority services, but mostly it was because they had experience of third sector carers' centres and services, and valued them hugely.

"Carers' centres are so important. Social workers cannot replicate this."

"So glad I found the carer's centre. It was raining and they were an open door for me. They can help me fight my fight."

"[The service] should be provided by a local independent carers' centre who can provide independent advocacy and advice, not by social workers."

If there is to be a duty placed on local authorities to establish or maintain information and advice services for carers, there will need to be a universal standard for carer information and advice services, which would be the minimum standard for any new services to provide. Carers must also play a central role in deciding who provides the information service in their area, taking account of existing services and recognising the strengths and benefits of existing services. This may be covered by the proposals around carer involvement in service planning and delivery, but the importance of involving carers in service design, planning and delivery must not be overlooked.

Local authorities will have to consider whether resourcing currently existing carer support services will be more appropriate than establishing a new service. The range of information and advice available from a service would have to be broad enough to cover a whole range of caring situations and all aspects of carer support. Independent carers' centres and carers' services can already provide expert information and advice at this level. In most situations, it will be better to support an existing service that has a well-known presence in an area, that carers already know and trust and that is skilled at identifying hidden carers and those who are new to caring.

"It's been proven in the past that if it's only one organisation's responsibility to provide info, that it can go wrong. We need as many people keeping us up to date as possible."

“The carers’ centres are well set up to do this work and their expertise should be recognised and paid for.”

“The carer needs this information to see what’s available and what their rights are etc. because the carer simply doesn’t have the time or means to gather this information.”

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

Carer Information Strategies are a good way of ring-fencing money to support carers and there is a risk that Health Boards may not protect money for carer information and advice without them. Carer Information Strategies have also been effective in raising awareness of carer’s issues within health services and we are concerned that without such a focus, the progress made will be lost. Carers and carers’ organisations must be involved in local planning if Carer Information Strategies are abolished – this is covered at a strategic level by integration strategic planning groups, but may not include carers and carers’ organisations in enough depth.

Support for carers from Health Boards must be maintained; if Carer Information Strategies are abolished, there must be a continued focus from the health sector in identifying, informing and supporting carers, including directing resources to carer support as a continuation of current CIS funding. Many Health Boards provide carers’ centres and other carers’ organisations with funding through Carer Information Strategies to provide information to carers.

Some carers were not really aware of the existence of Carer Information Strategies and were not sure how the proposed repeal would affect them, but many carers who took part in our consultation are broadly not in favour of repealing Carer Information Strategies.

“Health boards are still slow to understand the needs and role of carers and involve them fully. The duty to provide information keeps them focused on the existence of carers.”

“CIS required [to continue] at least until there is more evidence of how the integration of H & SC is working on the ground”

“Carer information strategies help ensure that money is used for carers. It is essential that carers and carer organisations are included at strategic level.”

“CIS: must get feedback from services so they know how much £ is needed, then ring fence it.”

The mechanisms for directing resources to carer support would need to be nationally agreed and embedded within the new integrated partnerships to ensure that health boards

and local authorities are able to respond to the requirements of their local communities. Carers and carer support services are not currently as involved in health and social care integration as they would need to be to ensure that funding and support is maintained. Additionally, it is not particularly clear from the consultation paper how integration of health and social care will replace the support that is provided and funded through Carer Information Strategies, even if the mechanisms for directing resources to carer support are embedded within the new integrated partnerships – we would need to hear more information on exactly how the Government would ensure that the funding they provide is protected.

“Recognise 3rd sector as equal partners in integration and give them the status they deserve in partnerships at a strategic level.”

“Need to continue and learn from good practice and share. This is an evolutionary thing that can be more integrated in the future.”

In addition, whilst supporting the capacity of existing carers’ services to provide information and advice to carers, local authorities, health boards and integrated bodies must also ensure that information and signposting to this and other support is also easily accessible to carers in a range of community settings.

“It is the local authority’s duty of care to the care to make sure that all relevant information is easy for the carer to obtain whether it be online or leaflets in GP surgeries, libraries, post office, hospitals etc. Maintaining and updating information is also important.”

“Not only should they establish and maintain an information and advice service but local authorities should be ensuring that carers know about it, promoting it far and wide, through voluntary sector organisations and community settings where carers and people go e.g. libraries, health centres, post offices, banks, shops, council offices, police stations, bus stops, local village shops etc.”

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

The majority of carers who either attended a consultation event or responded to our online survey indicated that they agreed with the proposal to introduce a duty to support carers and young carers linked to an eligibility framework.

“Carers are frustrated that they have a right to a carer’s assessment but no right to the support and resources they are assessed as needing”

This proposal recognises the need to support carers and places a statutory responsibility on local authorities to support them for the first time.

Carers were very keen that the legislation would reduce the inequality faced by carers across Scotland and lead to greater consistency in accessing support. However, they felt

that if each local authority was responsible for developing their own eligibility criteria, this would not reduce inequality and there would still be the potential for massive inconsistencies within the system, with carers from one local authority able to access a much higher level of service than those in another. They were comfortable with the idea that each area may develop different types of support, according to local need, but were not persuaded that there should be variation in the eligibility criteria. This view was unanimous across all of our consultation events.

Carers were clear that they wanted a right to support and greater transparency in regards to what level of support they are eligible for. They understood that by introducing an eligibility framework this could result in some people losing out, either because they do not meet eligibility criteria, or because the level of service they currently receive could be reduced. However, they felt that this was a fairer way of allocating resources and would help to address the postcode lottery and clarify what they were entitled to. National eligibility criteria must be co-produced by carers and specific to the needs of carers, rather being adapted from existing eligibility criteria for other care groups. National eligibility criteria will avoid further inconsistency in relation to the provision of services and support to carers.

The eligibility criteria must be linked to the needs of the cared-for person, but this should not be the only criteria determining a carer's eligibility for support. Additional factors must be considered, such as the carer's own health, employment status and desire to remain employed or seek employment, additional responsibilities outside the caring role such as looking after children, intensity of caring role, and being able to sustain a life outside of caring. Preventative support must also be taken into account as part of the eligibility criteria, to ensure that carers can access the support they need before reaching crisis point. Preventative support to carers can have a greater impact in the long run and also prevent carers from reaching crisis.

At the moment there is little consistency in what support is available to carers from one local authority to another. Indeed there are often inconsistencies in the support carers can access within local authority areas; some carers still struggle to access support despite having an intensive caring role.

*“Protects **all** carers not just carers who are lucky enough to live in a well-resourced area”*

“We need common sense legislation that ensures equality and maintains standards of support”

While the majority of carers support the proposed duty and believed it would produce positive outcomes for them, there were still concerns that it has the potential to result in some negative impacts for carers. Most concerns centred around the development of the eligibility framework, the successful implementation of the duty and what resources would be available to support it. Carers were also concerned that the eligibility to receive support may be set too high, meaning only carers in crisis would be able to access support.

There were also concerns that even if the duty to support was introduced, it would not be acted on and local authorities would not be held to account. This same view was also expressed by workers within statutory services.

Much of the success of the legislation will also be dependent on staff knowing about it and carers being informed of it. There is definitely a need for staff training; several carers expressed the view that this should be mandatory for all staff from statutory agencies.

“Where a duty is put in place, it is important LAs adhere to it. There needs to be sanctions for those who do not provide carers with their rights.”

“Concern that if cared for are unable to access services then it will be unlikely local authorities will be able to meet the needs of carers despite legislation being in place”

There should be a timescale between a carer meeting the criteria for support and that support being put in place. We would suggest that this does not exceed twelve weeks.

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

Yes

No

Carers and carers’ organisations would vastly prefer a duty to support carers, rather than a power. However, the issues discussed above regarding failure to meet eligibility criteria may arise. There was universal support for the proposal to retain the discretionary power to support carers in these circumstances. This would include forms of preventative support, such as support from a local carer organisations or condition specific organisation, short break voucher or grant schemes or signposting to local community support.

“There should be a duty to support carers against an eligibility framework, but local authorities should still have a power to support carers who don’t meet all the necessary criteria.”

We think that this existing power to support carers should be retained alongside the introduction of a duty, specifically to ensure support is available for carers who do not meet eligibility criteria.

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

Yes

No

We support the introduction of a duty to provide and promote short breaks. Carers who attended consultation events and responded to the online survey were in favour of this proposed duty.

“2 weeks to arrange a break (replacement care etc.), one week to have the break, 2 weeks to settle back in... Respite needs to be a real break for the carer.” (Carer, Oban)

Carers see this proposed duty as a way of achieving greater consistency in accessing short break services, having firm information on what they are entitled to and encouraging a greater focus from local authorities in developing quality short break services which would address their individual needs. Carers at our consultation events cited various barriers to not being able to access a short break, including lack of information, ‘didn’t

know about short breaks', being told they weren't eligible and there being no suitable provision available locally.

"Stop the endless waiting for a break, waiting for a person to leave to get their place"

"At present this is a postcode lottery"

"How otherwise will carers know about short breaks – not all carers are supported by a carers' centre."

The term *short breaks* is a confusing one for many carers and is not descriptive of the many types of support which can be accessed. Many carers thought that it only referred to support for the person they cared for provided outside the home, lasting for a few days, and were not willing or able to go on this type of break so were continuing to go without. Many carers explained that they required flexible services to accommodate their particular needs, so the definition of short breaks would need to be broad and this would need to be made clear in guidance.

In relation to the proposal to impose a duty on local authorities to publish and promote a short breaks statement there was a similar response. 93% of people who responded to our survey supported it and over 95% of carers who attended consultation events also indicated that they supported this proposal.

"The duty to provide short breaks linked to a requirement to produce a statement of short breaks availability at last brings clarity for carers to an otherwise confused situation"

The proposal to introduce a duty on local authorities to publish and promote a short break statement was seen as a positive way of addressing the lack of available information on short break provision. This was also identified as an issue by carers who contributed to *Rest Assured*² which found that not knowing how to access a short break was the most common barrier to receiving support (43%)

"Not enough clear promotion of short breaks is available, online or nothing is often the case and people still hear about services by word of mouth. Even when the local authorities provides or funds the service this is the case, definitely need to continue this provision and get a lot better at promoting it."

"All local authorities should have a shared directory of all available breaks, There should be equitable cross-charging across all local authorities (i.e. a shared resource)"

"L.As should be aware of the opportunities that exist in their 'patch' and should clearly state where all forms of support, help and respite are available. They should actively seek to signpost carers to a Centre where the most appropriate form of support will be ascertained and the carer supported to access them"

Stages and Transitions

² Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

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

Carers experience different challenges at different stages in their caring role, and recognising these challenges and planning for them (where possible) ensures that support provided to carers is appropriate and suitable. We agree that guidance for those agencies undertaking a Carer's Support Plan or Child's Plan will be beneficial for carers and ensure that changes in stages of caring are managed appropriately and where possible, planned for.

"All change is difficult to cope with and anything that can have planned transition intervention is to be welcomed. However it is also important to be able to react promptly to changes outwith transitional stages so that support is given when required most."

"The important thing is that carers should be involved in planning, implementation and management of such."

"They should also take account of the educational and employment requirements of carers and the effects of caring on costs, income, pensions etc."

Carers agree that guidance on managing stages of caring should be developed for those undertaking the Carer's Support Plan (or Child's Plan) – 95% of respondents to the online questionnaire were in favour of the introduction of this guidance. Carers must be aware and informed of their right to request a review to their Carer's Support Plan. However, sometimes a caring situation can change so quickly that relying on a Carer's Support Plan to manage these changes and provide the right support will not always be quick enough to support the carer. The guidance must specify what the procedure is for emergencies or unexpected changes to the caring situation, when support needs to be put in place immediately, and local authorities must be prepared to deliver this kind of support.

[...] "we do need local, flexible action, personal autonomy, and fast access to professional accredited resources like residential respite in an emergency."

"Carer support plan needs to be renewed regularly – there should be a duty to do this."

"They have to be committed that the information will be used to support the carer and the service user."

As discussed in our response to Question 4, we would like to see a commitment to ensuring that emergency and anticipatory care planning is always included in a Carer's Support Plan.

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

Young carers who become adult carers can face significant challenges. Adult carer support services are not always suitable for young people, who may be put off if other carers they meet through peer support groups etc. are older or do not have similar caring situations or lifestyles. Young adult carer services that work with carers aged 18-25 are not universally available across Scotland, although there are many areas of good practice. Carers are overwhelmingly in favour of the proposal to put a Carer's Support Plan in place for young carers before they reach 18.

"Young carers may not want to become adult carers so it is essential that they have the option. If the carer support plan is in place local authorities need to see what support if required for the service user in advance of any decision made."

"Well before they are 18."

Young carers who are likely to become adult carers should have a Carer's Support Plan agreed and that this should be carried out well in advance of the young person reaching the age of 18 so that the transition is as smooth as possible. We would suggest that the plan is put in place at least 1-2 years before they are due to leave children and young people's services.

"This should be implemented as a duty also or it will be the same scenario as transitions for young people reaching the age of 18. Nothing is done and when it is it's too late."

"I think YCs need support long before this so that they can make the most of their educational opportunities and not be swayed by those they care for into making decisions that will block their long term goals e.g. staying on at school, going away to university, taking employment away from home etc."

"Continuous support should not be compromised."

An initial assessment to ascertain whether a young carer will continue to care as an adult could begin even earlier, in line with transition planning for children with disabilities, which begins at age 14. Young carers who do not become known to social work services or young carer support services until after their 16th birthday should have a Carer Support Plan carried out as soon as possible, so the support will be available immediately as they become eligible for it.

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

Carer involvement is extremely important, as carers have the right to play an equal and active role in care planning and decisions, both on an individual level and in service planning for their local area. We believe it is important that carers and people who use services are involved in determining and sharing services in their community. However, proper carer involvement means talking to carers and making sure they are involved meaningfully and in a way that benefits them. Carers also need to be aware of the ways they can participate, and of their right to do so and be supported to do so.

Current involvement of carers in shaping services is patchy. In a survey of carers³, only a third felt that their involvement as equal partners in planning services in their area was good to excellent but half of respondents said that their experience was poor or very poor. Even fewer (27%) felt their involvement in discussions about service changes was positive, and 55% said that their experience was poor or very poor.

We therefore support the proposals to place a duty on integrated and non-integrated bodies to include carers in the planning, shaping and delivery of services. We believe it is important that carers and people who use services are involved in determining the types of support and services that should be available in their community. However, this involvement must be both meaningful and resourced.

“Provision should include: involvement of carers from a range of backgrounds – including “new carers”; affordable (free) and accessible opportunities to attend events; provision that reflects best practice standards for consultation with carers.”

“Carers should be given training, support, briefings to help them contribute effectively.”

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

Carer organisation involvement in planning, shaping and delivery of services in their area is equally important. This is covered to some extent in the Public Bodies (Joint Working) (Scotland) Act 2014, but to ensure adequate involvement, provisions need to be made in this legislation. We therefore support the proposals to make provision for integrated and non-integrated bodies to include carers' organisations in the planning, shaping and delivery of services. However, as mentioned in our response to Question 16, this involvement must be both meaningful and resourced.

“Recognise third sector as equal partners in integration and give them the status they deserve in partnerships at a strategic level.”

“...guidance re: members of the panel to create the joint strategic commissioning plan for Joint Boards is that the panels should be a person from health, one from the council and one from each locality being planned for. There is no guaranteed

³ Carers Rights Charter: Carers Survey which asked the views of carers on their knowledge of their rights and their experience of accessing them. 542 carers took part from across Scotland

place for carers' organisations. It may be that we can get a place via a locality but then are we representing that locality or carers?

Many carers' services are worried that even when they are included in local service planning, they will not have the capacity to do so. Involvement of carers' organisations must be resourceful and creative to ensure that a wide range of organisations (including the wider third sector) are able to participate.

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

This is important for carers and young carers as equal partners in care and expert providers of care. Support for carers and young carers will be at its most efficient and effective if it is planned and delivered to fit in with the support provided to the cared for person, so involving carers in the planning of this support (with consent) will benefit them greatly.

The principles of the Social Care (Self Directed Support) Scotland Act 2013 also reinforce the full involvement of carers in the assessment of needs for support for the person they care for and in the provision of support for themselves. Other existing legislation requires that local authorities take account of the views of carers in the assessment of adults and children before reaching decisions on what services or support to provide. This is to ensure that the care package meets the outcomes for the service user and the wishes and needs of both the carer and cared for person, as far as possible.

We support the Scottish Government proposal to enhance legislation to ensure that carers are involved in care planning for the person they care for and in shaping the support they need to help them manage their caring role and have a life outside caring. Our experience shows us that current practice can differ widely and too often, the level of involvement afforded to a carer is dependent upon the actions of an individual practitioner. We believe that provisions to ensure carer involvement in care planning will address variations and inconsistencies in local practice.

Carers reported that in some settings their experience was more positive, for example, in working with their GP, where more than half said that their experience of being treated as an equal partner in care planning was good or excellent. However, their experiences of partnership with other professionals were less positive. For example, there were significant levels of carers saying that their experience of partnership has been poor or very poor in hospitals (45%) and in care assessments (33%).

"GP is happy for me to attend appointments with my mother & explains treatments, medication etc. to me."

We believe that the knowledge and experience of carers should be recognised and valued in care planning and that they (and the person they care for) are the experts in deciding what services and support is needed. We also support the proposal that this principle is extended to young carers.

“Carers should have a right to be treated as an equal partner as they are the (safety) pin that holds the rest together.”

“It should be a legal requirement for carers to be involved and for their needs to be addressed.”

“It is crucial for carers to be involved when decisions will impact them as well”

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?

It is vitally important that young carers should have opportunities to become involved in shaping services in their local community. This can be done using age-appropriate methods, working in partnership with young carer support projects, the Scottish Young Carers Festival, and wider national young people’s organisations such as the Scottish Youth Parliament and YoungScot. We would welcome legislative provision that would enable greater young carer involvement.

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

Local carers’ strategies are currently developed by some local authorities to set out what their plans are to support carers and develop services in their local area. These local strategies do take the national carers’ strategy into account, but there is a lot of variance in local priorities and this can lead to services in some areas being very different to those available in other areas.

There should be statutory provision for local authorities and health boards to involve and collaborate with carers and carers’ organisations in developing a local carers’ strategy. These should be connected to the national Carers’ Strategy.

Review and update cycles should fit in with local and national planning to ensure that services are cohesive.

Young carers’ strategies should also be developed. This could be a distinct part of the carers’ strategy or a separate document, but the needs of young carers must be considered alongside the needs of adult carers in a local area. Not all young carers will be accessing children’s services and therefore may not be covered by a Children’s Services Plan.

Again, carer and young carer involvement in the development of carers’ and young carers’ strategies must be meaningful and adequately resourced.

“Carers organisations can represent carers. They can represent a range of views.”

Need a range of organisations, not just national organisations, need local knowledge.”

“Young carers need to be included at a formal and strategic level of local planning not just the informal routes of forums and Facebook Groups.”

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

We believe that local authorities should ensure that there are sufficient services in their area to meet carers' needs. There should be a definitive list of universal, free services that are available to all carers and that form the core services provided by carers' centres and services. This would be the minimum standard for services to provide for carers.

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

Identification of carers remains a challenge despite a wide range of initiatives designed to improve this. GPs are in a unique position to be able to identify carers who may be attending the practice to support the person they look after as well as attending for their own health needs, and therefore GPs and allied health professionals are perhaps the best placed people to identify carers at any stage in the caring journey. 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 into contact with.

The majority of carers (75%) who took part in the online questionnaire felt that both local authorities and GPs should have a duty placed on them to identify carers. 17% of respondents thought that only GPs should have a duty placed on them, and only 5% of carers thought that the local authority alone should have a duty placed on them to develop and maintain a carers' register.

We believe 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 this to be created. Whilst GPs holding a register of carers is a useful way of identifying carers in a particular local area, it is meaningless if there is no action attached to this. We would like to see a GP register linked to actions to support the carer, such as referral to a local carer support organisation and steps towards completing a Carer's Support Plan. There should also be a named person within each practice grouping to lead on carer

support to ensure that carers' needs and requirements are accounted for.

We see less value in placing the same requirement on local authorities as many carers may never come into contact with social work services. Where carers are in touch with their local social work offices, their details will be available on internal client recording systems either in their own right via a carer's assessment or on the community care assessment of the person they are providing care for (subject to changes proposed in this consultation paper regarding Carer's Support Plans.) The forthcoming integration of health and social care will provide an opportunity to develop integrated ICT systems to enable the sharing of information across GP practices and local authority social work departments. Many carers who took part in consultations felt that this would maximise the reach of a carers' register, rather than having separate registers.

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

Carers were in favour of the promotion of good practice amongst health boards. However, we believe this will only be effective if it is combined with the proposed legislation to maintain a carers' register and for health boards to monitor compliance.

"It may be more helpful to provide guidelines on what to do with the carers' register – its use, purpose, value, cost-effectiveness to the NHS etc. Advising carers to use their local carers' centre would be a simple and effective step for all carers. That raises awareness of the carer that they are a carer and that the centre is there to support them throughout their caring role."

"There is an over reliance on 'sharing good practice' without ensuring that it is incorporated within each local authority."

Good practice can be incorporated with guidance and other materials to support all agencies who are identifying carers.

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. Regular health checks for identified carers is an example of good practice that goes above and beyond simply keeping a register of carers who attend the practice.

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

Yes

No

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 into contact with. Whilst there are pockets of good practice within individual GP practices

in Scotland, particularly where these practices work closely with local carers' centres and carer support services, we believe that more stringent measures should be taken to ensure that all practices comply fully with the contractual arrangements, particularly as they receive funding for this through the GP contract. GPs should be required to report annually to their respective health boards on compliance with the GP contract. Reporting should include the number of carers identified within the practice, how many referrals have been made for a carer's assessment, and how many reviews of assessments have been undertaken.

The appointment of carers' leads within individual practices may also be beneficial. Many carers' services maintain close links with local GP practices, which can be very useful for those carers who do not wish to have a carers' assessment or who are not eligible for one, as they are able to access significant amounts of support from the carers' service. However, these links with GP practices are often supported by funding streams such as Reshaping Care for Older People, so their continuation is not guaranteed. These projects and initiatives would benefit from Health Boards monitoring the practice's compliance with the GP contract.

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)?

Current practice across Scotland differs when it comes to supporting carers who live in a different local authority area to the person they are looking after. Carers' views on this are evenly split, with some carers wanting the local authority in which they live to carry out their carer's assessment and provide any subsequent support; other carers believe that as the cared-for person's local authority is benefiting from the carer's presence and provision of care, it is this local authority who should support the carer. A proportion of carers said it should be a joint effort, with others saying that it should be the carer's choice, particularly highlighting that some carers are looking after more than one person in more than one local authority and it is not clear what people in this situation would have to do.

It may be more practical for the local authority in which the carer lives to undertake the carer's assessment and to collaborate closely with the local authority in which the cared for person lives, to make sure that the carer is involved in planning services provided to the cared-for person.

In some situations, the carer may eventually move from the local authority area they live in to the local authority of the cared for person. In these circumstances and where the 'original' local authority has carried out an assessment, we believe it would be beneficial for the carer's assessment outcomes to remain in place for a specified period whilst they are awaiting a new assessment from the new local authority. This will provide continuity of support to the carer to ensure they are not left unsupported. We would recommend that the period of time should not be less than six months.

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

Some carers were concerned that complex administrative arrangements (as discussed in paragraph 9.8 of the consultation paper) for recovering costs between local authorities may impact on the budget available for providing support to carers. Mechanisms are already in place for local authorities to recover costs from each other in relation to provision of support for the cared for person, but carers may feel more informed if local authorities are more transparent about these mechanisms. This should be covered in guidance as discussed in Q25.

The most important consideration for carers is that support is provided to them when they need it and that there is clarity about who to approach for support and review. Carers must not be passed between two or more local authorities whilst waiting for support – it must be clear which local authority is responsible for providing and/or covering the costs of support. It may be simpler if the local authority who carries out the carer's assessment is the one who covers the cost of support to the carer.

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

Yes

No

A change in the law will mean that guidance for local authorities is required. As it has been widely reported that several local authorities are intending to leave COSLA, it is important that those authorities who are not represented by COSLA are also covered by the guidance.

Additional Proposals: Hospital discharge

Spending time in hospital, either due to an emergency or a planned admission is often a time of concern and additional stress for both carers and the people they care for. This is consistently the case, both when it is the carer who is admitted to hospital and when it is the person they care for.

An admission to hospital often results in a person becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs.

Where a carer requires hospital treatment this frequently means they are unable to continue to provide care while they recover, or sometimes, due to ongoing ill-health they may no longer be able to continue their caring role or may have to re-evaluate the level of care they can provide

It is therefore essential that at these times carers have access to information and support, from the point of admission to discharge and that their views are fully taken into account when the discharge plan is put in place

“Carer support should be a part of hospital discharge planning and it should be available on discharge where appropriate.”

Stirling Carers Centre employs two Carer Support Officers based within the Allied Health Professional team at their local hospital. They work in partnership with NHS professionals to identify hidden carers at all stages of their hospital journey, helping them to navigate their way through the system from admission to discharge. The Carer Support Officers work with carers to enable them to be equal partners in care and therefore play an active role in the discharge planning process. This ensures that the patients and their carers leave hospital with the appropriate support in place to retain as much independence as possible in their communities.

MECOPP employ two Hospital Discharge Support Workers through Change Fund monies to provide dedicated support to BME older carers and those in receipt of care who are admitted to hospital. The purpose of the project is to: identify those who come into contact with acute healthcare services; support them to actively participate in the hospital discharge process; ensure they are referred to appropriate support agencies; and, are supported to remain within the home/community setting. The project works in partnership with a similar initiative provided by the City of Edinburgh Council and NHS Lothian.

Often when people are anxious to leave hospital they do not consider the additional support they will need when they are at home and the impact this will have on their primary carer and other family members. Taking the carer's views into account is key to ensuring that appropriate support is put in place, avoiding the risk of additional stress and carer strain.

“Nobody listens to the carer's advice when hospitals, rightly or wrongly, decide whether or not to send the cared for person home. This has to change.”

Poor discharge planning may also result in the person being re-admitted to hospital. The State of Caring Survey by Carers UK found that 37% of carers said that the person they care for was discharged from hospital too early because either support was not available or they were not ready to come home and 18% of carers surveyed reported that the person they care for had to go back into hospital within one month of being discharged because their health had deteriorated again and 8% within two months.

“My mum was discharged from hospital medical ward because she had onset dementia. I had my concerns about her going home to live alone and the hospital Social Work Department were unsympathetic. 4 weeks later my mum was re-admitted to hospital and is going through all of the same process as before. I have great concerns about her being discharged home again and I feel bullied by Social Work.”

Where the care provided by an unpaid carer is included within a hospital discharge plan, they should be able to specify how much care they are willing and able to provide. There should not be a presumption that family members will be available to step in and provide care on an ongoing basis. Planning needs to take account of the complexities of people's lives, such as their employment status, other responsibilities such as dependents and additional caring roles, their age and their own health and wellbeing. Unless carers are fully involved in discharge planning a full picture of what resources are required will not be achieved

*"I feel the carer should be consulted more. My father said he was ready to go home so he was discharged... I had to take 2 weeks off work to care for him full time."*⁴

*"I work full time as well as taking care of my husband who has MS. When he recently left hospital, I was not asked about the impact this would have on us, what help we had in place or if he would be able to manage in our home. He had to sleep on the sofa for 3 weeks following his release and had many bathroom accidents as both the bedroom and bathroom is upstairs and he cannot reach them. Very stressful for both of us"*⁵

When carers are also patients

Where carers are admitted to hospital their discharge plan needs to take into account replacement care to ensure they are not having to provide care which may be physically or emotionally demanding while they are recovering.

"Hospital discharge planning needs to include replacement care planning to ensure carers do not compromise their own recovery"

At our consultation events, there were several examples provided of carers who were forced to go back to their caring role before they were fit to do so, because there was no replacement care available. One person who had suffered several aneurisms was only able to arrange a few weeks care from an elderly relative in their nineties to support her husband. She then had to resume her caring role as her local authority failed to provide her with any support.

Another carer was advised he should take three weeks off from his caring role, following an operation, but his local authority only provided support for one week.

Even in cases where carers are able to access replacement care while they recover, this is sometimes taken from their existing short break allocation, with one carer who was in hospital on a drip being told: *"you've had your six weeks respite break this year"*⁶

Proposal for a duty on hospital admission and discharge procedures

Despite the existing Scottish Government protocol on hospital discharge, practice across Scotland differs widely and very often is to the detriment of carers. We strongly advocate that hospital discharge must begin at the point of admission with the full and active involvement of carers. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration.

Discharge planning must take account of the level of care that carers are willing and able to provide and should put in place additional support or replacement care where required.

We therefore propose a **duty on health to inform and involve carers in hospital admission and discharge procedures.**

Carers Trust Scotland

April 2014

hnoller@carers.org / 0300 123 2008

⁴ State of Caring Survey, Carers UK, 2013

⁵ Ibid.

⁶ Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008