

North Lanarkshire CARERS TOGETHER
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"Working for You"
Scottish Charity No: SC033795

11th April, 2014

Carers Branch (Consultation)
Adult Care & Support Division
Directorate for Chief Nursing Officer
Patients, Public & Health Professions
Director-General Health & Social Care
The Scottish Government
2ER St Andrew's House
Edinburgh EH1 3DG

Dear Sir or Madam

Please find enclosed the formal response from North Lanarkshire Carers Together to the Scottish Government consultation on its proposals for legislative measures to support carers and young carers.

The response was informed by the outputs from our annual Carers Conference in November 2013, the theme of which was *'Your Rights as a Carer'*, and from separate engagement events for adult and young carers that took place during March 2014.

Thank you for the opportunity to respond to this important consultation and we look forward with anticipation to the publication of the Carers Bill.

North Lanarkshire Carers Together will continue to work with the Scottish Government and other partners to deliver improved outcomes for carers and, hopefully, accelerate the pace of change.

Yours sincerely

A handwritten signature in black ink that reads "Sean Harkin". The signature is written in a cursive style with a large initial 'S'.

Sean Harkin
Carer Development Officer



CONSULTATION ON THE SCOTTISH GOVERNMENT PROPOSALS FOR CARERS LEGISLATION

NORTH LANARKSHIRE CARERS TOGETHER SUBMISSION

1. NORTH LANARKSHIRE

- 1.1 North Lanarkshire is the fourth largest Scottish local authority, located in Central Scotland - mid-way between Edinburgh and Glasgow. The 2011 census population for North Lanarkshire was 337,727. The population per square kilometre is 719 persons making North Lanarkshire the fifth most densely populated council area after the four city local authorities. Since the 2001 Census, the population has increased by 5%. This is the same percentage increase as seen in Scotland overall.
- 1.2 There are estimated to be 49,000 unpaid carers in North Lanarkshire providing care on a regular basis (Scottish household survey 2007-2008).
- 23% of carers provide 50 hours or more of care each week.
 - Over 70% of carers have been providing care for over five years
 - 11% of women undertake a caring role compared to 8% of men
- 1.3 Given the projected rise by 2016 of 21% in Scotland's 65+ population and 38% in the 85+ age group, the role of carers as equal partners will be critical in the delivery of care.

2. NORTH LANARKSHIRE CARERS TOGETHER

- 2.1 North Lanarkshire Carers Together was established in November 2000. It is a registered charity (Charity No. SCO33795) and, since 2005, a company limited by guarantee (Company No. 284126). The organisation's base is the carers' centre at 51 Hope Street in Motherwell. The organisation is a member of the Coalition of Carers in Scotland.
- 2.2 North Lanarkshire Carers Together exists because carers across North Lanarkshire wanted an organisation to represent their interests and to work to improve the quality of their lives. Carers recognised the need for a strong voice when talking to professionals and politicians about the services and policies that affect both them and the people for whom they care.
- 2.3 North Lanarkshire Carers Together aims to:
- be a potent force for change
 - raise the profile of carers and awareness of carers' issues
 - influence the planning and development of policies and services that affect carers and the people for whom they care
 - form active links between carers and professionals
 - establish innovative and productive consultation processes with service providers
 - promote the inclusion of all carers
 - represent the views of all carers, including the many young carers, in North Lanarkshire

3. CONSULTATION EVENTS

- 3.1 North Lanarkshire Carers Together hosted an event in the Hilton Strathclyde Hotel, Bellshill on Tuesday, 18th March 2014. The purpose of the event was to engage with carers on the Scottish Government's proposals. There were 60 participants on the day, 55 of whom were carers or ex-carers. The costs of the event were met by a Scottish Government grant and consultation materials were provided by the Coalition of Carers in Scotland.
- 3.2 At the event on 18th March, Moira Oliphant from the Scottish Government's Carers Policy Branch gave a presentation on the proposals for new legislation. There were further presentations by Robert Price, a parent carer from Motherwell, who talked about what the proposals might mean for carers and Claire Cairns from the Coalition of Carers in Scotland, who talked about the response to the proposals from the national carers' organisations and from carers across Scotland. Carers were then able to take part in facilitated, discussion groups on key themes within the Scottish Government's proposals. Carers also provided feedback on key questions using a message board set up for this purpose.
- 3.3 A separate consultation event took place on 11th March 2014 with 13 young carers from North Lanarkshire. The event was organised in a partnership arrangement between North Lanarkshire Carers Together and Action for Children – North Lanarkshire Young Carers Project.
- 3.4 The information from both consultation events and from the North Lanarkshire Carers Together conference '*Your Rights as a Carer*' on 4th November 2013 has helped to shape this response by the organisation to the Scottish Government's consultation on its proposals.

4. SUMMARY OF NORTH LANARKSHIRE CARERS TOGETHER POSITION

- 4.1 North Lanarkshire Carers Together believes that these proposals, if implemented properly, have the potential to make a significant, positive difference to the lives of carers. *Note: At the local consultation event on 18th March 2014, 55 carers (100%) agreed with this position.*
- 4.2 North Lanarkshire Carers Together believes that the health and wellbeing of carers transcends all other themes covered in the Scottish Government's proposals. With an ageing population comes an ageing workforce of unpaid carers. North Lanarkshire Carers Together feels that the following proposal should be considered for inclusion in the Carers Bill:
- **Carers health and wellbeing will be a public health issue** (Care 21 recommendation)
- 4.3 North Lanarkshire Carers Together supports the inclusion of the following Scottish Government proposals in the Carers Bill:
- A duty on local authorities to support carers according to an eligibility framework and a discretionary power to support carers who do not meet eligibility criteria. *Note: At the local consultation event on 18th March 2014, 55 carers (100%) thought there should be a duty.*
 - A duty on local authorities to provide and promote short breaks. *Note: At the consultation event on 18th March 2014, 53 carers (96%) thought there should be a duty.*

- A duty on local authorities to publish and promote a Short Breaks Statement. *Note: At the consultation event on 18th March 2014, 53 carers (96%) thought there should be a duty.*
- A duty on local authorities to establish and maintain a service for providing carers with information and advice on their rights, support and access to a carers support plan. *Note: At the consultation event on 18th March 2014, 55 carers (100%) thought there should be a duty.*
- A duty on local authorities to offer all carers a carer's support plan, including young carers who are about to turn 18. *Note: At the consultation event on 18th March 2014, 55 carers (100%) thought there should be a duty. At the consultation event with young carers on 11th March 2014, 13 young carers (100%) thought the local authority should provide young carers with a carer's support plan before age 18.*

5. RESPONSE TO KEY THEMES IN THE SCOTTISH GOVERNMENT PROPOSALS

5.1 Carer's assessment/carer's support plan

5.1.1 The carer's assessment should be renamed the carer's support plan. Carers told us:

"Carer's support plan' is better ... it is more descriptive ... it has a sense of purpose ... the word 'assessment' can be off-putting and intimidating it can be misconstrued as judgemental ... it has an association with 'means testing' it makes you feel that you may not be capable of providing care ... carer's support plan is more likely to be outcome focussed and to offer some of the supports needed along the way ... it doesn't matter what it's called as long as it leads to the support the carer needs."

5.1.2 The idea of a carer's support plan fits in well with the Carers' Journey tool used in North Lanarkshire, to engage with carers in order to identify their needs and the supports they may require. Carers told us:

"Asking any question is a form of assessment ... it is important to start the conversation early ... the Carers' Journey encourages engagement at an early stage ... it focuses on identifying, assessing and supporting carers in a personalised way it focuses on achieving good outcomes it does not supersede a carer's entitlement to a formal carer's assessment/carer's support plan."

5.1.3 Not every carer wants or needs a carer's support plan. However, all carers should have access to a carer's support plan and the local authority should inform carers of their right to access a carer's support plan. Carers told us:

"The carer's assessment is only of value if the needs identified are met ... if access to supports and resources follows on ... there should be a duty on local authorities and GPs ... and the NHS to inform carers of their right to a carer's assessment/carer's support plan."

5.1.4 The "substantial and regular" requirement should be removed. Carers told us:

"Nobody really knows what this means ... it can mean whatever you want it to mean it can be manipulated and used as a barrier to accessing support ... caring can't be simply measured in hours and days."

- 5.1.5 The alternative to removing the “substantial and regular” requirement is to clearly define it in guidance. Carers told us:

“It has to do with ... whether or not you live with and support the person for whom you care ... whether or not you are the main carer provider ... whether or not the person for whom you care would be at risk if you were not there ... and the level of that risk ... the level of support you are likely to need to carry on providing care for people with certain conditions e.g. profound physical and mental disability ... however, the same definition should be applied in every local authority area.”

- 5.1.6 The carer’s support plan should be separate from any assessment of the person for whom they care. Carers told us:

“A carer can still have support needs even if the person for whom they care is not in receipt of community care services ... some people have long term conditions but don’t receive social care.”

- 5.1.7 There should be a timescale for undertaking and implementing a carer’s support plan. Carers told us:

“There should be guidelines regarding assessment and outcomes ... assessments need to be carried out quickly as the process can be very stressful for some carers ... completed within two weeks of being requested ... carers should then be informed of progress ... carer’s support plan should be implemented within three months of the assessment being requested.”

- 5.1.8 Carers should be able to challenge decisions made about their carer’s support plan. Carers told us:

“There should be an appeals process ... for when ‘services’ are not agreed ... for when the “powers that be” disagree with you about the support you need ... carers need information about how to appeal decisions.”

- 5.1.9 It doesn’t matter who carries out the assessment. It is the quality of the assessment that matters. Carers told us:

“There should be clear outcomes ... carers want choice about who carries out the assessment ... carers centres will be better at carrying out a carer’s assessment.”

- 5.1.10 A lack of manpower or other resources should not be used as an excuse by local authorities for not undertaking a carer’s assessment in a timely manner. Carers told us:

“The integration of adult health and social care is an opportunity not a threat ... if carers don’t get the supports they need they will ‘crash and burn’ and there is a cost to this too ... local authorities should welcome the fact that they can devolve responsibility for carrying out assessments to the Third sector ... but they need to transfer some resources too.”

5.2 Duty to support carers according to an eligibility framework

- 5.2.1 There should be a duty on local authorities to provide support to carers according to an eligibility framework. Carers told us:

“But local authorities should still have a power to support carers who don’t meet all the necessary criteria ... we need common sense legislation that ensures equality and maintains standards of support ... the criteria for support need to be fair ... carers

should all be treated equally ... carers should be able to relocate to another area without having to be re-assessed ... a duty to support carers may not mean very much in the current financial climate! ... the money we save the health and social care system should be used to support us."

5.2.2 There should be a national eligibility framework. Carers told us:

"Criteria should be co-produced with carers at a national rather than local level ... otherwise it will be a post code lottery across Scotland ... again! ... the eligibility framework must ensure that all carers have equal access to supports and resources according to the criteria ... there needs to be eligibility criteria to ensure the fair allocation of resources."

5.2.2 Preventative support is still very important. Carers told us:

"We fear that resources will be diverted away from this to fund carers' support plans ... the budget for preventative support should be ring-fenced ... it's better and easier to prevent a crisis from happening than trying to manage it when it occurs ... self-directed support should be more accessible ... put more resources into support workers who could take some of the burden off carers ... more home care supports are needed to help with bathing and showering ... should be offered, not fought for!"

5.2.3 Carers' needs should be reviewed on a regular basis. Carers told us:

"The carer's assessment or support plan should be updated either 6 monthly or yearly by agreement ... the local authority needs to provide support for carers on a regular and sustainable basis rather than ad hoc ... the level of family and community support available to carers changes according to circumstances beyond the carer's control ... the population of carers is also getting older ... carers' health and wellbeing can deteriorate quickly ... many carers need some care as well as supports to carry on caring."

5.2.4 Eligibility criteria should primarily reflect the carer's needs but needs to take into consideration, where appropriate, the cared-for person's needs. Carers told us:

"Some cared-for people will state that they can manage without support when this is not the case ... the needs of carers are quite different to the needs of the people we care for ... support has to take into consideration the severity of the disability of the person being cared for ... need to take account of how stressful the caring role is ... needs to take account of the physical aspects of the caring role."

5.2.5 Carer's support plans should incorporate emergency plans. Carers told us:

"I need to know who will look after the person I care for if ... when ... I get ill ... or if I can't be here for any reason."

5.3 Duty to provide and promote short breaks

5.3.1 There should be a duty on local authorities to provide short breaks according to an eligibility framework and to promote short breaks. Carers told us:

"Local authorities should produce Short Break Statements that provide information about what is available where ... and how to access them ... make information available in local newspapers, health centres, post offices, supermarkets, local shops, churches and council magazines ... the Third sector should have a role in publicising and monitoring Short Break Statements e.g. Shared Care Scotland."

- 5.3.2 Eligibility criteria should recognise that all carers can benefit from a short break at some point in time. Carers told us:

“Eligibility criteria will ensure carers most in need of short breaks will receive them ... and help to protect carers’ health and wellbeing ... a carer is a carer no matter how many hours of care they provide ... entitlement to a short break should be proportionate to the level and intensity of the care you provide ... short breaks are essential ... but longer respite is also important.”

- 5.3.3 Eligibility criteria must be co-produced with carers. Carers told us:

“This has to happen if carers are really equal partners in care.”

- 5.3.4 Short breaks should be of a high quality and meet the needs of both carers and the people for whom they care. Carers told us:

“There is no point having the duty if the short breaks on offer don’t meet the needs of carers.”

- 5.3.5 A duty to provide short breaks must have sufficient resources aligned to it for it to be successfully implemented. Carers told us:

“There is no point having the duty if carers cannot access the kind of break they need ... when they need it ... carers save the state £10 billion per year ... invest to save!”

5.4 Carers as equal partners

- 5.4.1 There should also be statutory provision for carer involvement in care planning for service users. Carers told us:

“Guidance should define ‘equal partners’ ... carers are the ones with the expert knowledge of the cared-for persons ... nobody seems to listen to the carer’s advice when hospitals, rightly or wrongly, decide to send the cared-for person home ... this has to change ... carers must be involved in care planning to ensure their own interests and the interests of the cared-for person are taken into account.”

- 5.4.2 There should be statutory provision for carer involvement in the planning, shaping and delivery of services for the people for whom they care. Carers told us:

“Guidance should define ‘equal partners’ ... there should be visible and tangible outcomes from carers’ involvement in these processes ... there should be measurable outcomes to involvement of any kind ... carers are at the heart of these processes and must be included for them to be meaningful ... carers should have a right to be treated as an equal partner as they are the safety pin that holds the rest together ... the carer’s voice and experience is equally important to the evaluation of services ... there is no equality when carers are denied voting rights on committees ... carers should be included at board level in the new integrated health and social care partnerships with voting rights”

- 5.4.3 There should be a duty on local authorities and NHS boards to co-produce local carer strategies. Carers told us:

“Guidance should define ‘equal partners’ ... carer strategies must be kept under review and updated every three years ... local authorities must collaborate and involve relevant organisations and carers in the development of carer strategies ... carers’ organisations have large databases and can collect information from large numbers of carers ... and raise awareness of issues across large areas.”

- 5.4.4 Consideration should be given to each NHS board appointing an 'expert' carer to serve as a non-executive director. Carers told us:

"Guidance should define 'equal partners' ... 'equal partners in care' needs to be meaningful ... having a seat at the top table is important ... we need carers' voices heard in the boardroom ... a chorus of carers across the NHS ...there is value in significant, lived carer experience ... and experience representing carers' interests."

5.5 Information and advice

- 5.5.1 There should be a duty on local authorities to establish and maintain an information service for carers. Carers told us:

"There should be a duty and it should be based on a clear and consistent definition of a carer ... carers need to be provided with relevant information about services and supports that can help them to deliver care ... and about how to access them ... including short breaks ... and welfare benefits checks ... a record should be kept of all conversations with carers and this should be shared with them ... the information priorities are carers' rights, carer's support plan and short breaks provision."

- 5.5.2 If section 12 is repealed, the scope of local carer strategies should be widened to include the key themes of carer identification, information and signposting, previously embedded in NHS carer information strategies. Carers told us:

"Bring the funding streams together ... If there is no longer a requirement for NHS Carers Information Strategies, what happens to the money? ... carer strategies should be co-produced with carers ... in context of integrated health and social care planning ..."

- 5.5.3 Continue service level agreements with local carer organisations and carer centres to deliver carer identification, information and signposting. Carers told us:

"Carers centres should be commissioned to provide information to carers ... carers trust and value their carers' centres ... face-to-face communications are best ... without the formality that comes with dealing with statutory agencies ... information should be given at a pace that best suits the carer ... without an overload or bombardment of information ... allowing the carer to digest the information and to come back later if more information and advice is needed ... we are concerned that local authorities might put information services out to tender ... If I had not met the Carer Information workers from the (North Lanarkshire Carers Together) carers' centre at a Flu clinic, I don't know where I would be now ... carers' centres should take on devolved responsibility for providing information and advice ... they are more likely to be outcome focussed ... what will happen to the excellent staff and initiatives that are funded through NHS Carer Information Strategy resources when funding runs out in March 2015? ... or when section 12 is repealed? ... without these resources, carers' organisations won't have the capacity to take this work on."

- 5.5.4 Carer's should be informed about their rights. Carers told us:

"Carers should feel empowered within their caring role ... carers should be informed of their rights and how to access them ... I'm disgusted that prisoners have more rights than carers ... carers are relied on for their willingness, pride, ability (and ignorance!) to provide care."

5.6 Stages and transitions

- 5.6.1 Young carers who are likely to become adult carers should have a carer's support plan in place early enough to cover the transition from young to adult carer. Carers told us:

"Transitions planning should start early so that carers are well prepared ... especially important for parent carers ... carers need to stand up and challenge if their transition planning is not undertaken in a timely and appropriate manner ... people involved in planning and managing transitions need to have a high level of awareness and understanding of carers' rights and issues ... transitions are often badly managed with little if any consideration given to the needs of the carer ... a carer's support plan should be in place before the transition takes place."

- 5.6.2 Carers should be identified at anticipated points in the carer's journey e.g. when the cared-for person receives certain diagnoses. Carers told us:

"Often this doesn't happen ... nobody tells you that you have become a carer ... or what this means in terms of your own future ... identifying new and/or hidden carers is essential if carers are to adjust to their role ... effective communications and information sharing between and within agencies are crucial to supporting carers through transitions."

- 5.6.3 Guidance on the carer's support plan should cover managing stages of caring and transitions. Carers told us:

"Some transitions are predictable, such as giving up work or moving back into employment ... or the cared-for person moving into residential care ... or supported accommodation ... some are less predictable ... they may be the result of unforeseen changes in circumstances, such as family bereavements ... carer's support plans should be updated or reviewed as part of transitions planning ... parent carers need particular information when their child is leaving the Education system, especially regarding things such as advocacy and guardianship ... the carer's support plan should reduce the stress and workload for carers ... there should be named person to make sure this happens ... parent carers often do not receive the right information because professionals are not well enough informed about carers' rights and issues."

- 5.6.4 Transitional planning should take account of anticipated changes in family and community supports that will impact on the carer. Carers told us:

"Why are transitions still a problem for statutory bodies? ... they are generally predictable but rarely go smoothly ... take an anticipatory care planning approach ... think about different scenarios ... Getting it Right for Every Child is still not working as well as it should ... information should be made available on how to become a legal guardian when a child becomes an adult."

- 5.6.5 The carer's support plan should move with the carer between local authority areas. Carers told us:

"Carers should be supported by the local authority they live in ... it shouldn't matter where the cared-for person lives ... if there has to be cross-charging between local authorities, this should not require the carer's involvement."

- 5.6.6 There needs to be better introduction and induction of workers, such as paid carers, teachers and social workers, to people who have a learning disability. Carers told us:

“Learning disabled children face frequent transitions in respect to paid care workers given the high turnover of this group of staff ... familiar people often just disappear from their lives ... strangers just as suddenly appear ... exclusions from school can be very stressful for parent carers (usually mums) ... changes of teachers can be particularly difficult.”

5.7 Planning and delivery

- 5.7.1 There should be a duty on local authorities to produce local carer strategies. Carers told us:

“A carer strategy should be produced jointly by the local authority and the NHS ... it is logical to produce a local strategy as part of the integration of health and social care ... carers and carers’ organisations must participate as equal partners in care in the development of local carer strategies.”

- 5.7.2 Young carers’ strategies should be developed in conjunction with carer strategies. Carers told us:

“We need to get it right for young carers becoming adult carers ... this is the best way of considering the transition ... young carers and carers have many issues in common.”

- 5.7.3 Local authorities must ensure there are sufficient services in their areas to meet the needs of carers and young carers. Carers told us:

“Systems of support that are put in place around carers should not deteriorate or break down when workers move on. This is particularly important for carers of children with a diagnosis of autism spectrum disorder ... carer’s support plans should reflect best practice and ensure the carer’s needs are met ... they should not reflect ‘this is the best we can do within available resources’.”

5.8 Young carers

- 5.8.1 Local authorities should give young carers a carer’s support plan before age 18. Young carers told us:

“We need more support in our caring roles ... help us before things gets worse ... we need to be included in plans ... listen to us if we say we need a chairlift for a parent etc. ... we need more home visits and nursing support ... we need a more integrated support system ... include our feelings and ask us directly ... life would be less stressful with regard to education and work ... it would help to give us a chance to feel relief and be more supported ... start at age 16 ... understand we are more mature than you think ... but give us more leeway with our school work!”

- 5.8.2 The Scottish Government should accelerate the pace of development of the Young Carers Rights Charter. Young carers told us:

“We don’t know what to do or who to ask ... we don’t know about our rights ... let us know what rights we have ... young carers under 18 have less social development than other young people ... extra support ... and planned support ... would help our development.”

- 5.8.3 The Carers Bill should make provision for the inclusion of young carers in the planning and delivery of services. *At the consultation event with young carers on 11th March 2014, 13 young carers (100%) were of this view.* Young carers told us:

"We are just as mature as older people We have experiences so we know what we are talking about ... it would be beneficial to have a say ... we have different needs and circumstances to older people ... there is too much focus on older carers ... young carers need more help ... what is GIRFEC? ... we need to know more ... we need more presentations and workshops designed for young people."

5.8.4 There should be a named, long-term support worker for every young carer. Young carers told us:

"We need more projects like the North Lanarkshire Young Carers Project ... more social workers who understand and can help us ... doctors who know about us and our needs ... more questionnaires to let us tell you how we feel."

5.8.5 We asked how else the Carers Bill could help young carers. Young carers told us:

"Help us with the costs of caring ... the Education Maintenance Allowance and money ... make it easier for us to get Travelcards and discount cards ... give us help with the travel costs to schools ... a young carer's allowance and bursary."

"We need help to arrange family holidays ... Travelcard discounts ... short breaks... we don't know about what is out there to help us ... we need to be made aware."

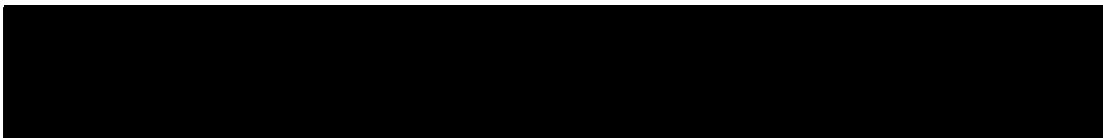
"Design services that work with the carer and the cared-for person ... the whole family ... GP support ... support in schools ... time for exams and assessments."

"Reduce our stress ... have more projects like North Lanarkshire Young Carers Project ... who do different things to support us ... and in school ... and in further education."

"We want to be made aware of our rights and to be recognised as young carers ... learn from the mistakes of the past ... we are the carers of the future ... tell us about our rights and we will tell other young carers."

"Allow for more attendance flexibility in school ... a young carer school card."

"Raise awareness of young carers in GP surgeries and schools."



Elizabeth Seaton
Chairperson

11 April 2014

Sean Harkin
Carer Development Officer/Acting Manager

11 April 2014

Directors of North Lanarkshire Carers Together

Elizabeth Seaton	Wishaw
Margaret Smith	Cumbernauld
Harry Robertson	Cumbernauld
Annabel Main	Cumbernauld
Ray Gardiner	Motherwell
David Hunter	Motherwell
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Management of North Lanarkshire Carers Together

Sean Harkin	Carer Development Officer (Acting Manager)
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