



CARERS CONSULTATION

Local Eligibility Criteria under the terms of The Carers (Scotland) Act 2016 Dumfries & Galloway

Produced by

**User and Carer Involvement and Dumfries and
Galloway Carers Centre**

January 2018

The Carers (Scotland) Act 2016

The Carers (Scotland) Act will be implemented from April 2018 and replace parts of existing legislation that supports unpaid carers (Carers). The Act will make it simpler for Carers to be identified as needing support with their caring role, and will make getting this support easier.

The key duty in the Act is that Carers who meet eligibility criteria must be provided with support to meet their identified needs. Each local authority must set their own local eligibility criteria - and must consult and involve Carers and representative organisations when developing the criteria.

The Act has a lot of focus on Carer Involvement – both in local strategy development and development of services, and in assessment and services provided to the cared-for person. There is also a duty on Health Boards to involve Carers in Hospital Discharge of the person they look after.

Carers Assessments will be known as **Adult Carer Support Plans** and **Young Carer Statements** (for Young Carers under 18). Both will focus on how the caring role is affecting the person - rather than the number of hours spent caring.

The Act specifies there must be certain things included in support planning for Carers, such as Emergency and Future planning, the Carer's Personal Outcomes, how much care the Carer is willing and able to provide, and whether any support could include a break from caring.

Each local authority must also maintain or establish an information and advice service for Carers. The services must provide information and advice about certain topics, including Carers' rights, income maximisation, advocacy, bereavement support, and emergency and future care planning.

The Carer's Centre and User and Carer Involvement

A joint proposal between UCI (User and Carer Involvement) and the Carer's Centre in Dumfries and Galloway was submitted to undertake the required work around engagement and consultation for Adult Carer Support Plans. Both agencies are well known in the region for their work with Carers and with legislative processes and procedures.

The Carer's Centre alone undertook the consultation with Young Carers and produced the report on same (see later).

At a meeting between the Provider and Proposers held on Thursday 28th September 2017, the following requirements were agreed:

- Proposer(s) must have knowledge of Carers and the issues facing Carers
- Proposer(s) must work collaboratively with all local and national Carer Organisations
- Carers of all ages must be engaged and consulted on this draft document relating to eligibility criteria (for example young Carers, young adult Carers and adult Carers)
- There must be opportunities for Carers in each locality to attend at least one face to face session in their locality
- There must be opportunities for Carers to engage through a wide range of media (including electronic means)
- Proposer(s) would lead a media campaign with support from colleagues in Planning & Commissioning
- National Standards for Community Engagement 2016 would be used
- The period of engagement and consultation would commence on 10 October 2017 and continue up until and including 15 December 2017.

Support

Support for the work as outlined in the specification included the following:

- Proposers were provided with a Young Carers Eligibility Framework and an Adult Carers Eligibility Framework
- The Proposers were provided with a list of FAQs and a series of broad consultation questions
- The Proposers were supported to access the statutory communications channels
- The Providers were supported to book venues free of charge (where available) in health and social care buildings if required.

Reporting

A full report (this report) on the feedback from the period of engagement and consultation was to be submitted to the Carers Programme Board before 19 January 2018. This report to include the following information:

- any relevant information from the engagement and consultation (for example comments and suggestions received, emerging themes)

- the number of people engaged with
- the location of engagement and consultation events
- the methods of engagement and consultation used
- details of protected characteristics where this has been provided
- evidence of work undertaken to engage and consult with 'hard to reach' groups.

Consultation and Engagement

Consultation and Engagement events were held in Annan, Dumfries, Castle Douglas and Stranraer for Adult Carers and other interested parties. Additional work was undertaken with Young Carers. The events were widely publicised and refreshments were available at all venues. Venues were booked by the proposers and were fully accessible.

Methods of engagement included working with existing groups that were held by the range of providers within the Carer's Interest Network. Good liaison with other agencies outwith the network ensured they were made aware of this work and invited to inform the people who use their services of the engagement opportunities. Additional marketing of engagement sessions was done both through the bidding agencies current network and included liaising with press and media outlets as appropriate and was included on the proposers' websites and social media pages.

An online survey (Survey Monkey) was provided by the funder and distributed through the networks electronically and in hard copy where appropriate. The results of hard copy surveys were collated by the proposers to inform this final report.

Adaptations to any documentation to make it more accessible were undertaken by the proposers.

WRITTEN QUESTIONS AND ANSWERS

(At CC and UCI Hosted Events in Annan, Castle Douglas, Dumfries and Stranraer)

Total of 30 attendees.

Q1. As a Carer, does the Eligibility Document explain the different levels of support you might receive in the future, and how it will be decided?

Yes – 12

No – 4

Summary of Responses

There are concerns that the Eligibility Document does not give enough detail on certain issues. For example, how and when a Carer will move between different levels of support? Who decides what level of support they require? And so on.

- Clear pathway, but it doesn't address problems of accessing support.
- It's very difficult to understand the way it is going to work if the person you care for's support needs fluctuate. What are they going to do for that Carer & cared-for person? Are they going to be ignored when in green and only booted into the system when in crisis?
- Someone unfamiliar with service jargon could easily be put off.
- Could go into more detail as there is a lot still to be discussed
- It's not clear enough for me. I need it explained in 'bitesize' pieces. At what point green moves to amber to red etc. As a Carer it's hard to ask for help - so if I ask it's important I get it.
- I find triangle too rigid - caring is fluid.
- It explains the different levels of support - but I think the decision-making process is a bit vague. Who exactly will make the decision on eligibility? And therefore the support given?
- Who decides and then makes it happen?
- The different levels of support are clearly explained. However, I do not, see, or understand how it will be decided.
- Yes - but feel it needs explained to Carers who are new to their caring role. Could be overwhelming if left to get on with it yourself.
- Who will decide?
- Although it shows the different levels of Support it would be nice to be proactive and look at what is available to stop going from green to yellow, yellow to red. How can it be identified early?

Q2. Do you feel the Local Eligibility Criteria are properly targeted to ensure you will get the support you most need?

Yes – 8

No – 5

Summary of Responses

Of the 30 attendees, 17 didn't tick yes or no – perhaps suggesting the majority were undecided. Other than that - concerns continued to be raised around what might be an individual's rapidly changing support needs. How quickly can/will the system respond and the support be put in place? Will the system be flexible enough to meet real-life needs and emergencies?

- Need to address "levels of desperation" as well as more practical, visible criteria. Asking about health all too often just gets us thinking about our physical health. ACSP got to the heart of my levels of desperation. These criteria don't.
- What happens if the cared for person has not yet had a diagnosis or are waiting for one? Will you be known as a Carer at all?
- The targets don't seem to make any mention of fluctuating needs. The support I need would be yellow or orange, to stop me getting into the red in the first place
- Targeting the support needed does not mean you will get it.
- Unfortunately my experience has clouded my judgement - so "no". However, I have found the support from the Carers Centre has kept me sane. I hope the criteria will help Carers feel more empowered.
- I find it surprising that Day Care eligibility is in the Specialist Support Area - i.e. the "critical" area. I think it should be in the Targeted Support Area.
- Life situations dictate that one can move from universal support zone to specialist support very quickly.
- How will they ensure I get the support? Getting any support is a struggle.
- Worry a wee bit about the word "ensure". Hopefully it will - but who will "ensure"?
- As long as there is somebody able to look at your level of support and decide if it is the correct level, Carers should be asked what support they would like.
- I find personally that Local Eligibility Criteria changes like the weather, and it depends on who you speak to. It needs to be set in stone so people know what it stands for, and be explained well.
- Only if there are enough people to carry out the support.
- Further support needed.

Q3. Do you think there is anything else that should have been included in the Eligibility Criteria, or anything that should have been left out?

Yes – 13

No – 3

Summary of responses

Once again, concerns are raised around the lack of detail, and the greater need for emergency planning. For example – what will happen if the Carer is suddenly incapacitated? More detail required regarding decision making process. How to access immediate support? And concerns that the criteria are focussed more on physical than mental health.

- More looking at emotional and psychological health, not just physical. However this is covered to some extent in "How you feel"
- Fluctuations of conditions? What about Mental Health? This needs to be better titled e.g. The Carers mental health? When health is mentioned it's often seen as just physical.
- Accessing short term, immediate support. How to assess eligibility if you care for 2 people, or are both cared-for and a Carer?
- Carers deserve a better support network than currently exists. Contacts for support should know the Carer and acknowledge their needs.
- I think that at some point in the Adult Carers Support Plan some form of emergency/contingency plan is discussed (it may already be) e.g. if the carer is suddenly incapacitated - what happens - is there a plan put in place for that eventuality?
- Where to get the support once you are eligible?
- I think it is all covered and can't think of anything that should be left out.
- In red triangle of support - "carer no longer wants to continue caring". It shouldn't be assumed that even with the correct support the Carer wants to continue.
- It should identify what people need to get by in life and not be seen as a "wish list". If it does become a "wish list" it won't get off the ground.
- More detailed information regarding Self Directed Support.

Q4. Is there any other comment you wish to make?

Yes – 12

No – 2

Summary of responses

In times of crisis, Carers may need support to recognise the types of support they require. More comments around the issue of communicating with Carers in language they will understand. Also, the need to tell Carers whether or not there will be any “means testing”. Concerns about how this support will be paid for in a time of budget cuts.

- Someone, somewhere must work out, for the stressed out Carer, what would help. Sometimes carer is too stressed to know the answer.
- Some people are both cared-for and Carers? What support is there for them?
- What about pre-diagnosis people? If your cared-for person doesn't have an assessment or diagnosis of a condition that requires support or causes a carer stress, will the Carer even be able to convince anyone they are indeed a Carer?
- Targeting the support needed does not mean you will get it.
- Found group/forum really useful, learnt few new things that I may pursue. If we have the right support, we won't go into red when crisis hits.
- Session today was interesting and pleasant but feel it wasn't clear what was expected - more of a support group.
- I would hope that the Adult Carer Support Plan will be made available to all carers, and displayed information in G.P's surgeries, social work offices etc. and also advice of its existence given by social work staff to carers. I think many people "slip through the net".
- Information overload - too much jargon. Self-help group of people with similar problems sounds promising.
- All the law and paperwork is great but getting someone to implement is another story.
- As I'm fairly new to being a Carer, I have been well treated thus far. I have no idea what the future holds but feel confident that if/when I need further support it will be forthcoming.
- Hopefully the "triangle" will make a difference in identifying the needs of Carers. It will only be effective if those who have the power to change things i.e. s/w implement the changes. Listening and hearing what the Carer is saying is the most valuable tool.

- Carers should be told that this is not means tested. What support the cared for person receives should not alter the Carers level of support. Many agencies will have to be involved in this for a satisfactory outcome for Carers.
- It is a great idea. I hope it is managed well to support the "Carers". Needs to have better Communication Strategy to reach out to *all* Carers - not just ones who are on the radar.
- More consideration for Carers. Someone to contact in an emergency (their emergency). Perhaps a local newspaper with articles on "how to" be a Carer and what's available for that Carer etc.
- I know all this is to ensure Carers needs are met, but will the resources be available when extra support is needed?
- Promises are fine, but how will they pay for it when budgets are being cut?

INFORMAL COMMENTS

Noted during discussions around the eligibility criteria and consultation

Annan - 6 Carers

"They offer what you don't want, and don't offer what you do want."

"Is this act going to make any difference to access to respite?"

"We've had no respite in 5 years. Someone has to die before mum can go to care home for respite."

"Without respite there is a tipping point and I will end up needing for both my parents to go into care."

"SDS is such a hassle and when you are on the edge it is too much. I could not take on another layer of stress."

"Everyone has a different breaking point – some of it is very subjective."

"ACSP reviewing should be built in."

“Things often tick along & then you’re suddenly thrown into crisis - fluctuating caring needs and how to access different levels of support needed.”

“Do they recognise the difference between caring for someone with ‘static’ illness and those with fluctuating symptoms?”

“Who decides the situation has gone from green to orange, or orange to red? Is it the GP?”

“Too late to ring alarm bells by the time you get to red - should be in amber. Who should make decisions when it reaches crisis on both sides? Someone in authority – perhaps a clinician?”

“Support from carers centre and service CPN should be 24/7. Even Carers Support e.g. Crossroads only available until 6pm so evening outings are impossible.”

“Services need to take more attention of Carer’s distress.”

“Is any support available if caring for somebody without a diagnosis?”

“I feel that framework is specifically geared towards physical health.”

“When things moving from orange to red, needs crisis intervention by clinicians/professionals – including discussions with the Carer within 24 hours re management and support.”

“Once things are in the red, you need someone to take immediate control and find out how to help you, rather than asking what you think you need.”

“On the forms, it shows 3 tiers in the triangle of care, but 5 levels of criteria in what is contained within an Adult Carer Support Plan. Should be consistent...”

“Re the Criteria – it simply says “Health”. Should say Physical, Intellectual, Emotional and Social Health.”

Castle Douglas - 4 Carers

“Some people are scared to speak up. Theyre frightened of losing what they have for Self Directed Support.”

“Is respite means tested – do we have to make a contribution?”

“Annual review for Carers would help – could be alongside the cared-for persons review.”

“Competence to care – end up firefighting situation – how to identify if you are better prepared than someone else.”

“Look for strengths and weaknesses individually - needs to come before crisis. G.P perhaps to see if the carer will need specific or additional support and flag this up. Carers need to feel they are capable of undertaking the caring tasks.”

“Reaching carers is the biggest challenge.”

“Not given enough info on what support is available. (This comment made by a G.P.)”

“No longer allocated an individual at Social Work - so have to repeat history to each person you speak to.”

“Lose count of the number of times you have to tell your story.”

“Too many people may be involved in providing care e.g. agencies sending many different people.”

“Have to get to crisis point before anything happens to support carer or the cared-for person’s situation. Perhaps if support had been available before this I could have continued to care but my husband is now in care – I couldn’t cope.”

“Assumption always made that you will care regardless if you want to or not.”

“It will always come back to the availability of staff/care.”

“Carers don’t know what support is available to them.”

“Information needs to be in the triangle – Point of contact.”

“Run articles on Carers issues in local newspaper. 300 words a week.”

“Panic button for carers! Carer Call...”

“Telecare – why is it in the triangle?”

“Should be a First Responder in each area.”

“Still an attitude from professionals that ‘they know best’. There’s a reluctance to accept there is an (unpaid) EXPERT alongside the professional!”

Dumfries - 6 Carers

“Daughter 16 but has mental age of 5 and was admitted to Ward 7 and then 14 and patient’s family were not given the option to stay on the ward as would have done previously in children’s ward.”

“In DGRI, if parent has to be there they should be treated as a Carer and offered food.”

“Does NHS recognise difference between visitor and carer – do they have a policy?”

“Budgets need to be focused on Carer needs, and not be confused with budgets for cared for.”

“Assumption is often made that when cared for person is out - or being cared for by someone else - that this is respite for the carer.”

“Staff attitude very negative towards carers getting respite. This should be taken into account and not assumed as being taken care of. I would like to go out at weekend but this is not considered.”

“Green at the moment - but could go to red at some point.”

“Situation changes overnight to red – but can be so stressed that you don’t realise it – need someone to help with this.”

“Social work staff do not call back.”

“Carers support gets put on hold if cared for person is in transition e.g. to adult services (cared for is taken into account, but not Carer).”

“Feel Carers are not given recognition or consideration in G.P practices although they promote carer stuff in posters etc.”

G.P can’t discuss the cared-for person’s “problem” with Carer!

Stranraer – 12 Carers and 2 Service Users

“A DECISION MAP would be a great help – pointing you in right direction – a bit like a drop-down menu on a website. Only want information on your type of caring - don’t want to have to wade through stuff that isn’t relevant.”

“Documentation could be clearer - shouldn’t be a challenge.”

“Transport is a problem. Can’t always get to where support is provided.”

“Mum and child (with autism). When child is stressed, mum is stressed. Better care for the “service user” would ease the load on the carer.”

“Some people are unwilling to accept support – or unaware support exists.”

“In a progressive illness – things change. Also, often no warning pre emergencies.”

“What happens when there’s no beds?”

“Can be caring for one elderly and a grandchild – fluctuating and varied needs.”

“Lack of respite is a huge problem!”

“Continuity of care – difficult enough to see a GP, let alone the same one twice.”

“Stable – Crisis – Declining – all need different plan types.”

“More help needed with “signposting”.”



Young Carers Project, Dumfries and Galloway Local Eligibility Framework Consultation 2017

In order to carry out a consultation with Young Carers on the Eligibility Criteria which is required as part of the Carers (Scotland) Act 2016 which will come into force on 1st April 2018, the original document needed amended into more child friendly language and a version that explained the reason for it. (See appendix 1)

The method of consultation that was used was postal questionnaires and group discussion with individual responses. The postal questionnaire on reflection was not a good method to use as it included the information on the consultation and the questionnaire to be returned. (See Appendix 2) The feedback from the Young Carers was that they needed someone to explain the document and the results below show that the response rate was poor. At the groups it allowed a member of staff from the Young Carers Project to take the lead in explaining what the Eligibility Criteria was and the reasons behind it, this in itself sparked off conversations and questions from the Young Carers.

Postal Questionnaires

- Total Sent Out = 217
- Total Returned = 6
- 3% response rate

Group Consultation

- Total number of groups = 5 throughout the different localities of the region
- Total number of YCs attending groups = 32

Responses from Postal & Group Consultation

1. As a Young Carer do you feel that the Eligibility Triangle explains the different levels of support you might receive in the future and how it will be decided?

Yes	36
No	2

Comments:

- It could be a bit more understandable
- Areas of support is clearly laid out
- It allocates each type of support into an easy to understand table
- More understanding words and pictures
- It's confusing
- It could help a lot

2. From looking at the Eligibility Triangle do you think that the different levels of support that Young Carers could receive are correct and would meet your needs?

YES	34
NO	4

Comments:

- Any and all support is covered
- I believe that the different levels are well selected

3. Do you think that there is anything else that should be included in the Eligibility Triangle or anything that should be left out?

- No x 22
- It's alright x 3
- Don't know x 3
- Yes x 1
- Think should get funding every year instead of every 18 months
- I don't think anything needs to be changed or added
- I think it is already perfect
- Unsure as I am not very familiar with what other people's needs are
- Unsure as to what should or shouldn't be included
- Include Child Line
- I think everything I need is in the Eligibility Triangle

4. Is there anything else you would like to share with us about the Eligibility Triangle?

- No x 23
- I don't understand this x2

- Its fine
- It makes sense
- Do the Young Carers get a say in this
- Its good
- I like it
- I feel it may work better as a column chart
- It could be easier to read
- It's ok but I don't think it is needed
- Make it easier to understand x 2
- Confusing
- I feel I understand what is being said
- Do we get a say in any of it
- I would of liked to have learned more about the eligibility triangle

From the above results of the consultation the below points highlights the recurring themes by the Young Carers

- The Eligibility Triangle clearly highlights the different levels of support that Young Carers are entitled to.
- Some Young Carers feel that it was not easy to understand what the Eligibility Triangle was about – this could be related to the age range that was consulted on, it is difficult to capture a level of understanding that is suitable for 7 – 18 year olds in one document.
- The younger age range highlighted that having pictures and easier language would be of benefit.
- There was a slight recurring theme of the document being confusing

Taking into consideration the results of the consultation it is concluded that the general consensus of the Eligibility Criteria consultation with Young Carers across Dumfries and Galloway is that it will meet their needs depending on what stage they are at and levels of support required. However it is not seen as being an easy read document for the Young Carers and would need explained to them the reasons for certain decisions being made – this would be best placed for professionals involved in their lives to do this.

APPENDIX - SURVEY MONKEY