

Respite Policy Consultation Summary and Actions

Consultation period: 6/1/20 to 14/2/20 (date extended due to requests for more time, additional consultation events facilitated)

1) Consultation Summary

Public consultation meetings held:

- Balavanich 15/1/20 (8 attended)
- Stornoway 17/1/20 and 6/2/20 (20 attended)
- Tarbert 23/1/20 (11 attended)
- Castlebay 14/1/20 and 29/1/20 (5 attended)

Consultation meetings with individual groups:

- Caraidean Uibhist 30/1/20 (1 attended)
- Disability Advocacy Collective group 12/2/20 (20 attended)
- Speak Out group 12/2/20 (15 attended)
- Third Sector Interface 13/2/20 (10 attended)

Submissions received by email:

- Five submissions from local groups (Crossroads Harris, Harris Carers, Advocacy Western Isles, Social Work assessors and Autism Eilean Siar)
- Twenty submissions from individuals

Summary: Ten consultation meetings were held with 90 people attending and twenty-five submissions of feedback were received by email

Consultation was also published on the websites and feedback incorporated into this document.

2) Summary of feedback on Respite Policy

Key questions arising:

- Is the policy useful?
- Should there be a scoring system in the respite policy?
- Is the scoring system appropriate?
- Are the maximum respite levels appropriate?
- What information needs to be added to the policy?

Is the policy useful?

- 'A lot of the policy is good'
Noted
- 'It would be useful to have a flowchart to explain the process' (**Action: Add a process flowchart to the Policy**)
- 'Local resources should be addressed first before doing the policy'
The Policy is required to operate within the resources as delegated to the Integration Joint Board and Educations, Skills and Children's Services. Resources allocations are dealt with

through the established governance process of these organisations. Budgetary provision is not addressed within the remit of this Policy.

- ‘The policy is about carer resilience rather than child needs’ **(Action: Add statement that respite will be designed according to the needs of the cared for person)**
- ‘Needs more child policy, it is carer focused’ **(Action: see above)**
- ‘The needs of the looked after person do not appear to be used in this assessment **(Action: see above)**
- ‘Carers already feel unvalued, unseen and unappreciated and this policy formalises that’
The Policy makes explicit the value of carers and the support they provide and references the commitment to support carers as defined in the Carer Strategy. The Policy reconfirms the commitment to carers through statutory duties.
- ‘Make the policy autism-friendly’ **(Action: Prepare an ‘Easy Read’ version of the policy)**
- ‘The policy is overly complex and the complexity of the policy is likely to make the process very slow to administer and cause unnecessary anxiety to carers’.
The Policy will be embedded in practice applying the statutory timeframes for assessment, the increased transparency the Policy affords will enhance rather than delay the assessment process
- ‘The scope of the policy should be defined ie all age groups’ **(Action: Add statement that policy covers all age groups)**
- ‘It would be useful to define what the policy means by “Carers”’ **(Action: Add definition of a ‘Carer’ per the Carers Act 2016 to the policy)**
- ‘There needs to be a different approach between elderly people and young people’
The Policy enables the application of the personal circumstances be these age related or other factors to be accommodated as well as the statutory duties associated with the relevant service user group.
- ‘I find it astounding that (younger) adults are being conflated with the elderly when it comes to looking at respite provision!’
The Policy covers all adults and enables the personal circumstances to be reflected in the assessment and the commissioning of the service
- ‘In relation to the aim of policy, why Reablement and not Enablement **(Action: Add ‘enablement’ to the aim in addition to ‘reablement’)**
- ‘Will the Local Eligibility Criteria be replace by the new scoring system or sit alongside it **(Action: Clarify how Eligibility Criteria links to scoring system)**
- ‘SDS isn’t a choice to be offered, it is the vehicle through which all choice should be offered. The document needs to at least give the simple four options and not rely on a web link elsewhere’ **(Action: Update SDS paragraph and Alternative Respite paragraphs to clarify)**
- ‘Has the Short Breaks Statement changed – if so how? It now seems to stipulate replacement care from family and friends ahead of CNES support, which is not acceptable **(Action: Update Short Breaks paragraph to clarify)**

Summary: The feedback is that the policy is useful but amendments are needed. Five actions have been taken to amend the policy in response to feedback.

Should there be a scoring system in the respite policy?

- ‘It is good that it will be transparent’
Noted

- 'There is a danger that a scoring system loses the nuance in assessment'
The tool is part of the assessment process not a sole determining factor, it is an indicator of need not a scoring tool
- 'Good to see a scoring system'
Noted
- 'Would appreciate a scoring system for fairness'
Noted

Summary: The feedback is that there should be a scoring system in the policy and no actions are required.

Is the scoring system appropriate?

- 'Scoring system is ok'
Noted
- 'The Scoring system is useful'
Noted
- 'The scoring system needs to take account of the needs of the child'
The tool is focused on the carer but will reference and link to the child's assessment and plan
- 'Respite is vital where there is more than one child in the family and the other has challenging behaviours (**Action: Change wording of level four in scoring criteria number nine to clarify that an additional highly intensive caring role is relevant**)
- 'Eligibility thresholds need to be lower within the scoring system'
Eligibility thresholds have been agreed 2018 following consultation and link to the national eligibility criteria
- 'The threshold of the criteria needs to be dropped as it is set too high'
See above, the Comhairle and Integration Joint Board commission carer services for low and moderate thresholds and universal supports
- 'There is a general feeling that the criteria are too strict and that some of the carers will have reduced levels of respite with the new policy'
See eligibility comments and the commitment to no reduction in service capacity, the process for review of needs and the escalation process for 6 weeks plus of respite services. See associated actions in relation to alterations to indicators of need.
- 'Critical level one should not be a level, the carer should not be in a caring role if they reach that stage'
Carers choice to undertake a caring role is a personal matter and not for services to determine. The caring role can be gradual increase in care or immediate due to a life changing event. The commissioned services for and those subject to this Policy provide supports respecting the level of need and enable acceptance of a range of services. (**Action: Consider removal of subset within levels.**)
- 'A carer would be unable to care at critical level and therefore that level is superfluous'
See eligibility criteria comments, carers are currently supported within this category to sustain their role
- 'Anybody fitting into the scoring category of "critical" would not be able to care. Therefore the critical category should be removed from the scoring'
See comments above

- The screening tool should be adapted for different people'
The tool is adaptable to reflect individuals personal circumstances and as stated is not the sole process for assessment
- 'Carers who live 24/7 with the cared before person should automatically get respite'
As defined in legislation all carers are entitled to a carer support plan or young carers statement. Respite is not a universal service and is targeted based on eligibility. The process will capture the 24/7 caring role
- 'There is a general feeling that if you care for someone 24/7, then there should be automatic right to respite'
As stated earlier, respite is not a universal service but is targeted at those sustaining care arrangements 24/7 as defined in the eligibility criteria
- 'Do both the service user and the carer need to be assessed as critical or substantial, this is unclear?'
No, the assessment will reflect the circumstances of both, the carers needs are the focus of this policy and are not always determined by the cared for's level of need
- 'If you're critical in one area, you should be critical across the board'
The indicators within the tool allow a true reflection of the caring role on the individual, assumptions would not be appropriate. It is a holistic assessment of need across a number of indicators.
- 'Some areas such as health & wellbeing, relationships, life balance, overnight support needs and challenging behavior should carry more weight'
The tool is not considered on its own and the full assessment and plan will reflect the most pertinent factors impacting on the carer
- 'How long a person has been caring isn't taken into consideration'
This is included in the assessment – duration and intensity
- 'Prevention is a more resource effective approach than cure. Those scoring below the threshold are still presenting behaviours that will likely worsen without support and will inevitably end up above the threshold'
As stated earlier other services are commissioned to support universal access and low to moderate need based on third sector engagement with carers
- 'Some concerns that eligibility levels would be hard to reach. Given the very slim line between and the very subjective interpretation of the four levels, the scoring criteria need more detail to ensure fairness and transparency'
Opposing view to that shared through previous comments. As stated earlier the eligibility criteria has been consulted on locally and relates to national policy. The indicator tool is not the sole assessment tool.

In relation to scoring criteria number one 'Health and Wellbeing (Physical)':

- 'CNES's role should be make sure that no carer leaves the right-most box ie no risk
Complete elimination of risk is not feasible given the context of the service, the Policy will enable risk to be addressed based on an individual's preferences and circumstances

In relation to scoring criteria number two 'Health and Wellbeing (Emotional and Mental Health)':

- 'What is the difference between "wellbeing is breaking" and "significant impact"?' **(Action: Amend wording of level three to clarify)**

In relation to scoring criteria number three 'Relationships':

- 'The relationship bits in the system are confusing'
- 'Two important relationships are strangely incorporated into the one question here. The carers relationship with the cared for person should be assessed separately from the carers relationship with "other key people in their life" **(Action: Amend wording and move 'key people' relationships to criteria number eight)**

In relation to scoring criteria number four 'Living Environment':

- 'Scoring system makes no reference to people living alone'
This Policy is for carers, if they live alone this will be included in the assessment.

In relation to scoring criteria number seven 'Future Planning':

- 'Low risk and no risk are exactly the same' **(Action: Change Level description 0 to reflect carer being completely confident)**

In relation to scoring criteria number nine 'Number of other dependents':

- 'Where there is more than one child, assessment should take this into account **(Action: Change level description 4 under 'Number of other dependents')**

In relation to scoring criteria number ten 'Number of other carers':

- 'How did you come to the conclusion that one unpaid carer managing one person scores 4 whilst three or four carers struggling with one person scores 0?'
This is not a conclusion reached, the assessment process will consider all carers and the impact their role is having on them and the appropriate supports

In relation to scoring criteria number eleven 'Weekly formal support':

- 'Whilst waiting for a care home bed it means they have been assessed for 24 hour care yet again they score 0 here if they have more than 15 hours formal support in the community'
The process will focus on the impact on the carer, noting the care plan in place for the cared for to give holistic view of the caring role

In relation to scoring criteria number twelve 'What level of personal care needs to be met by the Carer':

- Change level 1 to 'Minimal support with practical and personal care'
- Change level 2 to 'Some areas of practical and personal care'
- Change level 3 to 'All areas of practical and personal care'

(Action: Amend levels per above and change level 0 to no support required with practical and personal care)

In relation to scoring criteria number thirteen 'What level of care from the carer is required overnight?':

- all the levels should move up one ie level 3 should be level 4 etc

(Action: Amend levels to reflect impact of overnight care)

In relation to scoring criteria number sixteen 'What levels of challenging behaviour are evident?'

- 'This isn't very clear – challenging behaviour in the cared for person or the carer'

(Action: Amend wording to clarify that this is the behaviour of the cared for person)

Summary: The feedback is that the scoring system is not wholly appropriate and amendments are required. Eight actions have been taken to amend the policy in response to feedback in 'Is the scoring system appropriate?'

Are the maximum respite levels appropriate?

- 'Respite at these levels will be too low unless there is flexibility of hours throughout the year'
- 'The need for respite should not be capped'
- 'Weekend respite is important and needs to be fairly distributed'
- 'Three weeks isn't enough for someone who meets substantial'
- 'Don't change the maximum levels of respite'
- 'Eight weeks of respite is important'
- 'The drop from critical at 42 nights to substantial at 21 nights is too much'
- 'It seems that carers have to have already reached breaking point, physically and mentally, in order to be eligible and this strikes me as utterly absurd'
- 'Moderate criteria should be set higher ie critical'
- 'Moderate risk is not eligible for respite, yet it is described as needing intervention – this is counter-productive'
- 'Increase the respite to at least twelve weeks'
- 'Everybody should get eight weeks respite'
- 'Those in the moderate category need respite and moderate risk should be substantial and substantial should be critical'
- 'Are children who are on a residential placement term time and home for holidays entitled to respite?'
- 'I disagree with the downgrading of the maximum amount of respite provided. If anything, it should be increased'

Summary: The feedback is that the maximum respite level should not be reduced from eight weeks and that respite should be provided where risk is assessed as moderate. Substantial is set at 28. See previous comments regarding eligibility criteria, targeted services and universal services. The Policy enables all carer roles as per the legislation to be addressed through a carer's support plan and young carers' statement. There is no set entitlement for respite currently and the Policy includes an escalation process for an increased level of support. The Policy is intended to support the aspiration to have a transparent approach to allocating the available resources.

What information needs to be added to the policy?

- A link to the current committee report on care costs
(Action: This is published annually and will be linked to the Policy)
- 'Respite has an educational function and this should be included in the policy'
The commissioned respite service will reflect the cared for person's desired outcomes.

- ‘The policy needs to capture what the current resource is and how any deficiency would be dealt with’
Unmet need due to capacity will be managed in line with current governance processes.
- ‘It would be useful to take onto account transition needs in the policy’ **(Action: Add section on transition between children’s and adult services)**
- ‘Include a section on transition’ **(Action: see above)**
- ‘Do the numbers apply for transitions?’ **(Action: see above)**
- A statement on the provision of transport to respite needs to be included **(Action: Add section on provision of transport)**
- ‘Take into account the travel times for daytime respite especially for the remote and rural areas’ **(Action: see above)**
- ‘Policy needs to include a protocol on emergency respite’ **(Action: Add section on provision of emergency respite)**
- ‘Need to outline processes for emergencies and concern about respite’ **(Action: see above)**
- ‘Respite capacity should have flexibility for crisis’ **(Action: see above)**
- ‘Include a section on dealing with someone refusing to leave a respite’ **(Action: see above)**
- ‘Right of appeal regarding allocation’ **(Action: Add section on appeal procedures)**
- ‘Include a reference to right of appeal’ **(Action: see above)**
- ‘List of effective supports should include advocacy’ **(Action: Add advocacy to list of supports in final paragraph)**
- ‘Include a section on short-breaks within the policy’
(Action: This is already published and a link will be appended to the Policy)
- ‘What constitutes capacity?’ How will risk be managed within the waiting system?’
Capacity was expressed as the available respite services. Risk will be managed as it is currently is in line with social work practice and duties.
- ‘Within the area of resource allocation flexibility should be mentioned: families allocated respite hours at times of the day that don’t suit them are really not being helped at all. Budgets that are so closely tied to people’s health and wellbeing should have flexibility built in so that services can be offered when they are most needed, not when they are most convenient to the council’
There is not an unlimited service capacity for social work and social care services. Best use of the available resources as well as escalation of exceptional circumstances will continue to be the practice. Future commissioning will be informed by further discussion with the Carer Information Strategy Group as agreed at the recent meeting, specifically to understand and address the reasons resulting in the lack of uptake of allocated respite.

Summary: Four information sections have been added to the policy in response to feedback

3) Issues raised in relation to respite in general rather than in relation to the new policy

Adult Services:

- ‘Rowantree in Balavanish and lochdar Care Unit could be used to increase capacity for respite in the Southern Isles’
- ‘There are no emergency beds available in Uist’
- ‘Using care homes for respite is not always appropriate for young adults’

- 'There is inequity in rural areas'
- 'Help unpaid carers find more sources of support such as a one-stop shop or a pop-up carer centre'
- 'Increase the number of respite beds'
- 'Risk of families not taking in commitment if support is not available'
- 'There are so few respite services on the islands, can mainland services be used instead'
- 'Breaks together with family members are also good'

Children's Services:

- 'PEF summer activities should be open to all'
- 'Respite dates should given six months in advance'
- 'Clarity is needed on new respite unit in Sandwickhill'
- 'Consider the Point side of Mackenzie Park for new respite unit'
- 'Create new respite unit for children'
- 'If a new children's unit is built we would need to protect the respite places within it'
- 'SDS system works well and does not need changed'
- 'Use of SDS limits the hours of respite'
- 'Due to block purchasing carers are unable to purchase enough support from providers via a direct payment'
- 'Increase the numbers at Hillcrest for respite'
- 'Respite is a necessity, not a luxury'
- 'There should be a fair share of weekend respite'

Summary: Feedback was received in relation to respite provision rather than specifically the policy and this feedback has been passed on to management as appropriate.

4) Comments on further consultation

- 'Carers would like to see the modified policy after consultation before it is ratified at committee, so they can make final comments'
The agreed process is through the Carer Information Strategy Group and its members ahead of circulation to the appropriate governance through CnES and the Integration Joint Board.
- 'If a change to the current proposals are made, then they should be consulted on, otherwise the consultations and submissions made will be for a version that doesn't exist and presumably wouldn't be taken into consideration when decisions were being made'
The feedback from consultation is used to inform the final draft of Policy, ahead of the Carer Information Strategy Group input. There was no commitment to public wide consultation being repeated.

Summary: Two requests were made for the amended policy to be further consulted on, this will be done through the Carer Information Strategy Group.