

## **Respite Consultation Summary**

**The consultation ran from 24<sup>th</sup> October 2017 to the 16th January 2018. 44 individuals or carers responded** to the **respite** consultation either online or by paper. A further six written responses and two verbal responses were received totalling **52 responses**. Four of the six written responses were from a professionals working within adult social care/CCG and one was received from the Hornsey Pensioners Action Group.

**Three drop in sessions** were held during the consultation period at the following locations: 1) Hornsey Library (1st November – 9.30am -11am), Marcus Garvey Library (20<sup>th</sup> November – 6.30pm – 8pm) and Wood Green (11<sup>th</sup> December, 11.00-12.30pm), in total 8 people attended these sessions. Two focus groups were held with young carers on 4<sup>th</sup> and 11<sup>th</sup> December, in total 20 young carers attended.

Of the 44 **individuals or carers** that responded, the following quantitative results were obtained:

1. 45% agreed with the definition of respite care, 39% reported that they were unsure, 11% reported that they did not agree and 5% did not respond
2. 52% understood the difference between respite care and other short term care, 23% reported that they were unsure, 20% reported that they did not understand the difference and 5% did not respond
3. 45% thought the proposed policy would have an impact on them or their carer's ability to provide care, 32% reported they were unsure, 13% reported it would have no affect and 9% did not respond
4. 34% understood when and how the Council charges for respite care, 20% reported they were unsure, 39% reported that they did not understand and 7% did not respond
5. 32% reported that the policy was clear and easy to understand, 27% reported they were unsure, 32% report they it was not clear and easy to understand and 9% did not respond

### **Qualitative responses**

When asked what was missing or needed to be changed within the policy, the main points from those who responded were:

#### **Definition**

- The definition of respite in sections 3 and 7 implies that respite only applies when the carer can no longer provide care to the cared-for person. It is therefore missing the understanding that respite provides a break from caring both for the carer and cared for as part of an ongoing relationship.
- The focus on respite covering “what happens when a carer cannot provide care in the short term,” does not fit parent carers of disabled children who will require periods of respite over a number of years.
- Clarity required on reference to holiday away from home in terms of what the Council/CCG will and will not fund, for example in terms of additional costs required to cover the cared for person's needs.

#### **Eligibility**

- The policy should be clearer about who gets respite and state what tests are applied to determine who is eligible for respite and why.
- There should be a set amount of respite per year which the carer can use without the need for extra assessments.
- The policy needs to include information explaining that a service user does not have to be eligible in their own right to receive respite. If the respite is the only way to meet the needs of the carer and the carer is eligible, then respite should be allocated.

### **Entitlement**

- It is not clear how much respite the carer is entitled to and how respite is accessed.
- More information is needed to explain how much funding a carer/cared for person would receive, for example, does everyone receive the same amount?

### **Charging**

- It is not clear how the charges will affect individuals
- More information is needed about what happens if an individual is unable to pay
- Additional clarity is needed on when the rolling year starts.
- Individuals who receive aftercare services under section 117 of the mental health act are exempt from charging for respite services.
- The policy needs to include information that where care for the cared for person is jointly funded by the CCG and the Council, there will be no charge for respite care commissioned by the CCG. Charges are apportioned according to the percentage split for joint funding agreement.
- Some respondents felt that carers should not be charged at all.

### **When respondents were asked whether the policy would have a negative impact on them or their carer's ability to provide care, the following points were raised:**

- Where respite arises due to an emergency need such as hospitalisation, this should **not** be included in the overall allocation of respite. If a carer subsequently loses some of their respite allocation because the cared for person requires replacement care, this could have a negative impact on the carer.
- The need for repeat assessments can be off putting and result in disagreements.

### **Other Comments**

- Policy is welcomed, carers need a break.

- The policy is not always easy to understand and needs to be simplified.
- Consideration should be given as to whether respite allocations should be based on need bandings e.g. low, medium, high which would help determine the allocation respite.
- The policy needs to be clearer on the cost implications for both families and the Council/CCG.
- Top up policy implications should be explained further, including examples of third party organisations.
- Young carers under 18 and older carers over 18 needs should be separated into separate policies as access routes; charging; eligibility are very different.
- There should have been more opportunity for the policy to be co-produced with service users
- Concerns were raised around the provision of respite care, in light of the recent closures of day centres and a residential setting.
- More work is needed support carers, from identification to publicising and promoting carers assessments/entitlement to providing information, advice and guidance.

## **1) Drop-In Sessions**

**Three drop-in sessions** were held during the consultation period at the following locations:

- 1) Hornsey Library: 1st November 2017 9.30am -11am
- 2) Marcus Garvey Library: 20<sup>th</sup> November 2017 6.30pm – 8pm
- 3) Wood Green Library: 11<sup>th</sup> December 2017 11.00-12.30pm

in total 8 people attended these sessions.

Comments about the draft policy

- Agreed with the definition of Respite Care stated within the Policy.
- The policy should include a brief explanation about Haringey Clinical Commissioning Group and what the organisation does.
- Attendee suggested that Principle 4 in Section 5 of the draft policy includes carers and the cared for person in the decision making i.e. in addition to working with health and social care partners staff will also work with the cared for and the carers for their best interests.
- The draft policy doesn't seem to be very supportive of carers.
- Attendee commented that it would be difficult for the group to agree to Section 6 of the draft policy without being familiar with the Children and Families Act.

- More clarity is also needed around eligibility criteria. There needs to be scope for reasonable adjustments or flexibility depending on individual circumstances.
- More clarification around whether the respite care budget will be included in the personal health budget or allocated separately. Carers need to be informed on the exact amount being provided for respite care.
- More detail needs to be included around Haringey's top up policy, mentioned in Section 8. Include examples of who is considered as third parties.
- There should have been an opportunity for the policy to be co-produced with service users.

## **2) Young Carer's Feedback**

Haringey Early Help & Prevention Service carried out a consultation with young carers in December 2017 on the final draft of Haringey's Respite Policy for carers.

Two focus groups were held with young carers on 4<sup>th</sup> and 11<sup>th</sup> December 2017, in total 20 young carers attended.

### **1) What roles would you cover?**

- Running Errands i.e. going to shops, weekly shopping
- Personal care i.e. dressing, bathing Personal care i.e. dressing, bathing, assisting with medication
- Childcare i.e. looking after siblings
- Household Chores i.e. cooking, taking rubbish out, mopping, washing up, washing clothes etc.

### **2) When would you need cover?**

- When I am not at home i.e. at school, at clubs, at school trips, at friends
- When I don't know how to do something
- Wellbeing when I am not well
- Emotional i.e. when I am feeling sad

### **3) How do you currently access cover for your role?**

- I don't get any support with cover for my caring role
- Other family members help out when I'm not able to
- I don't know how it's accessed but my mum gets support from a carer

### **4) Does this policy make it clear how you would access replacement care?**

- Yes, it does make it clear, but only after it was explained to us as the language used is not very young person friendly.