

APPENDIX C



RESPITE REVIEW DISCUSSION QUESTIONS & COMMENTS



**RESPITE SERVICE REVIEW
DISCUSSION QUESTIONS**

July 24, 2018

DISCUSSION QUESTION #1:

In session one, we shared **the former HRC Respite policy** in addition to the respite policies for all 6 other regional centers in Los Angeles County. Please discuss the HRC service policy:

- Do you think there is anything important that is not addressed in the HRC policy?
- Do you think there are parts of the policy that need clarification?
- Do you think there are any important concepts in the Lanterman Act provisions related to respite services that are not referenced in the HRC service policy that should be added?
- What other suggestions do you have for changes to the policy?

DISCUSSION QUESTION #2:

We previously discussed the **respite assessment tool** that is currently used by HRC. We also shared a draft of a revised respite assessment tool that HRC is considering using and we are interested in receiving your input on these assessment tools.

- Is there any additional information that should be added?
- Is there anything that you think should be deleted?
- Do you have some general guidance to provide concerning the assessment tools?

DISCUSSION QUESTION #3:

We reviewed a **respite booklet** that HRC uses to help families understand what respite is and what they can expect from the respite services they receive.

Although we will not have time tonight to fully revise this booklet, please discuss in general:

- What are some major areas that should be added?
- Is there anything that you think should be deleted?
- Do you have some general guidance to provide concerning the use of this booklet?

DISCUSSION QUESTION #4:

In session two, we heard directly from three **respite service providers** concerning how they provide their services.

- Do you have some comments, recommendations, general guidance related to respite service provider issues?
- Is there anything that you would like to share regarding your ability to access this support?

DISCUSSION QUESTION #5:

Please use this time to make any observations, raise any questions, or make any suggestions concerning HRC Respite Services.

**Harbor Regional Center
Respite Care Policy Review
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Comments from Kathryn Platnick

Thank you for investing the time to review the Respite Care purchase of service policy. My family really appreciates the amount of time you have taken for this process.

HRC Policy Comments

I have reviewed the corresponding policies for every LA County regional center. Based on that review, I offer up the following suggested changes to the HRC policy for consideration:

Definition.

Some policies have additional clarifying language that I thought was useful in helping someone understand the purpose of respite. Here is language from the proposed WRC and SCLARC policies that I liked:

“Respite is provided only to minors or adults residing in the home of a family member who is responsible for the 24 hour care and supervision of the individual. It is not intended to meet a family’s total need for relief from the on-going care of a disabled family member or as a substitute for day or after-school care for working parents.”

Philosophy

The existing HRC policy stated philosophy is generally fine, although I am not certain it is correct to assume that most families can meet their respite needs through natural supports (the second sentence of the first paragraph). Also, it seemed to me that it would be helpful to mention the overriding philosophy of respite, which is to keep disabled family members in their family home if that is where they have chosen to live. I also thought it might be useful to mention the criteria used to determine respite needs.

Based on those ideas, I offer this great introductory statement I found in the ELARC policy:

“Parents of children with developmental disabilities are expected to provide the same level of care for them as they would for a child without disabilities. However, when a child has special needs parents often face challenges beyond those they might encounter with a typical child.

In order to provide caregivers with the occasional relief they need to keep the child in the family home, [HRC] may provide respite care when medical, physical or behavioral needs cannot be met by other family members or a regular babysitter."

Policy

Just as a matter of tone, you might consider changing the lead in to the policy section to read:

"HRC may purchase respite care for families if the following criteria are met:"

Of course the policy needs to be modified to address the new lift of the cap on respite services. It would be helpful to understand how HRC has come to the conclusion that the appropriate monthly maximum is 40 hours.

Also, the policy needs adjustment to reflect the "quarterly" approach to respite as opposed to monthly limits that result in loss of hours.

As for the second item 2, there was discussion at the first meeting about the use of respite care to pay for recreational camp. It appears that NLARC has attempted to address that issue in its policy by use of the following language:

"Cost-effective out-of-home respite service options may include temporary residential services, vendored weekend program (Saturday program), and other services designed to provide planned relief from the ongoing care and supervision of the consumer."

Lastly, several policies mention that the actual respite care provider can be selected by either the contracting care agency or by the consumer. I thought it would be helpful to include that idea. SGPRC has some decent language:

"Respite care shall be provided through the use of a vendored in-home respite or home health agency. The consumer may choose the option of selecting his or her own respite worker so long as that individual is employed by a vendored respite agency."

Other Documents

Respite Needs Assessment Tool

The proposed matrix is MUCH easier to follow than the existing respite needs guideline. That said, I note the following points that you might want to address in the proposed matrix:

- Issues of mobility are not really addressed other than the reference to “needs help with transfers” in the high need column of self care
- I think the items in the low need box for several categories are actually 0 based items rather than 1 point, especially self care, medical and family support
- What guidance is there for determining if caregivers are emotionally resilient or need emotional support?
- The issue of age of caregiver (over 60) ought to be included in the family support section

HRC Service Policy—General Standards

I don't recall seeing this policy before. Does it relate to a particular service? How is it otherwise used?

Making It Happen Brochure

Generally, I thought this one of the better HRC flyers I have read. My comments are:

- Page 3, first paragraph: I think the commentary about respite workers creates an unrealistic expectation. Although they are trained, this is ultimately a minimum wage job with high turnover and an employee base one can expect when someone is not being paid adequately for their work.
- Page 8: This page may need some adjustment to account for the move to “quarterly” hours rather than monthly hours and the potential use of respite hours outside of the home (like camp).
- Page 10, first full paragraph: I was surprised to see the statement that you cannot use more than 8 hours of respite on any given occasion. Is that true? Where are consumers advised of this limitation?
- Page 11: Again, need to modify last section to account for quarterly hours.