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Karen Hatch
Family Support Council Member

Emily Manire
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Ellen McCahon
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Tammy Mills
People First of New Hampshire

Deb Opramolla
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Lauren Ramsey
Brain Injury Association of NH

Cathy Spinney
Area Agency Board Member

Mary St. Jacques
Institute on Disability



April 7, 2023

Erica Ross-Skianes
Program Planner III, Office of Client and Legal Services
New Hampshire Department of Health and Human Services
105 Pleasant Street
Concord, NH 03301

Re: HeM 505 Comments

Dear Erica,

Thank you for the opportunity to comment on the proposed changes to HeM 505, Establishment and Operations of Area Agencies.

As you may know, due to the short timeline for comments (15 business days), the full Quality Council was unable to review and comment on the proposed changes. Instead, the Council reviewed comments on the current rule and tasked the Rules and Regulations committee with finalizing the comments on behalf of the Council.

As time allows, the full Council will review the proposed changes to HeM 505 during the formal comment process and send additional comments as needed.

He-M 505.02 Definitions

(k) Consumer

The Council is concerned about the current definition of consumer. This term is more typically used to describe the user of services and does not include their relatives or guardians. We recommend that BDS reviews how “consumer” is used throughout the rule to be sure that the voices of people with disabilities are specifically included.

In addition, the Council recommends that “supporter” is included in the definition to reflect the use of supported decision making and that support is included throughout the rule wherever there is a reference to guardian or other places where appropriate.

He-M 505.03 Role and Responsibilities of the Area Agency

The Council is concerned about a number of the new responsibilities of the area agency as outlined Section a. In a number of these, it is not clear who has the responsibility to take action when problems are identified. What is the responsibility of BDS? What is the responsibility of the area agency? If the area agency is expected to address issues, what is their authority, particularly now that service providers will be contracting directly with Medicaid?

- a(7) Providing oversight and management of the provider network by:*
- a. Coordinating and monitoring the provider network to support the needs of the catchment region as outlined in the agency's area plan, developed pursuant to He-M 505.02 (f).*
 - b. Communicating relevant service delivery system updates to providers.*

The Council is concerned about this language and the implied responsibility of the area agencies to ensure the state has an adequate network of providers. In addition, there are practical concerns with how this will be operationalized considering that area agencies may be serving people across the state as will provider agencies.

In terms of 7(b), is every area agency expected to communicate with every provider in the state? Will providers receive the same update multiple times from different area agencies? This seems difficult to manage and inefficient.

a(13)d Assessing annual satisfaction with, and review and continuous improvement of, quality of services.

This is another provision of concern. How are area agencies expected to ensure continuous improvement of services when they are not providing the services? What will happen if an area agency determines that quality services are not being provided? Will they have the authority to do anything besides make a referral to BDS? We recognize that the details of these processes will likely be outlined in policy documents, but we are concerned that this does not create an adequate framework to guide how this will actually work in practice.

a(13)f. Collaborating with the Community Mental Health Center that serves the region to ensure coordinated service planning and delivery for individuals accessing or wishing to access services from both service systems.

The Council does not believe that this is happening now in most areas of the state and we are concerned that this brief mention of this as the responsibility of the area agency will not change the status quo. This is a large gap in services for individuals with some of the most significant disabilities.

a(14) Increasing access to employment by:

- a. *Acting on employment trends, as identified by the Bureau.*
- b. *Participating in the employment leadership committee pursuant to He-M 518.*
- c. *Providing data to the Bureau regarding employment of individuals not less than quarterly.*

The Council strongly supports efforts to increase the employment of individuals with disabilities. We are concerned about how this will be operationalized. What are the area agencies expected to do to “act on employment trends”? How will area agencies gather data? Gathering data seems more appropriate to expect from service coordinators. We strongly encourage the state to devote additional resources to expand all opportunities to increase employment of people with disabilities, including opportunities for career advancement, higher wages and more hours.

a(15)f Ensuring area agency availability 24/7 in order to support critical incident assistance.

The Council is concerned about crisis management. People with disabilities and families facing a crisis need one number to call for help, not three or four. We strongly believe that the rules should identify one organization who is responsible for organizing crisis support so that people with disabilities will know who to call and that person can figure out all the details of which organization is responsible for what.

a(16)e Promoting advocacy programs on behalf of individuals including ensuring the delivery of two trainings per year on advocacy and individual rights.

Who will be required to go to these trainings? Are you intended that area agencies support self advocacy organizations or family advocacy organizations with this provision? The Council strongly supports this requirement, but believes the language needs to be clearer and stronger.

a(20) Managing guardianship activities by:

- a. *Providing technical assistance regarding guardianship needs for individuals.*
- b. *Completing the request for the establishment of a public guardian if a service coordinator is not available.*

This section should also include a requirement that the area agency provides technical assistance regarding supported decision making and alternatives to guardianship and that the area agencies maintain a list of attorneys who can assist families if needed.

a(22) Completing information gathering via survey by:

- a. *Disseminating and coordinating the annual National Core Indicator satisfaction surveys.*
- b. *Reviewing survey results to identify areas of quality improvement.*
- c. *In partnership with BDS, distributing and reviewing survey results to ensure continuous quality improvement for our comprehensive service delivery system.*

The Council supports gathering information about the quality of services via the National Core Indicator satisfaction survey, but this language does not indicate who is responsible for actually acting on areas where quality improvement is needed or how they will be held responsible for such. In addition, the Council would like to receive regular reports on the data gathered and action taken from BDS and the area agencies.

(d) When possible, the area agency shall utilize generic, integrated services, rather than establish separate services for people with developmental disabilities or acquired brain disorders.

The Council is concerned about the use of the word “generic” in the above. The Council recommends replacing it with “community-based”. In addition, we believe this is an opportunity to emphasize that these services should be developed through the use of person centered planning.

(e) The area board shall establish policies and procedures for the governance and administration of the area agency and all service components of the area service delivery system. Policies shall be developed to ensure efficient and effective operation of the local service delivery system and adherence to requirements of state and federal funding sources, the area plan, and rules and contracts established by the department. Policies shall be developed to ensure that the area agency avoids any conflict of interest and any appearance of conflict of interest in its business relationships.

The Council is very concerned about transparency of area agency policies and procedures and believe that all policies and procedures impacting families or governance should be published on the area agency website and made available to people with disabilities and families by request. This same requirement should be included in the provider rule that’s being written now.

Additionally, the Council believes that it would be helpful to clarify that the agency’s strategic plan may be used to satisfy this requirement as long as it meets required criteria in this section and throughout the document.

The next section of the rule involves governance and the area agency Board of Directors. The Council is concerned that this language, “(4) Members shall be representative of the agency’s different consumer groups and entire area” is not sufficient to insure the inclusion of the diversity of voices for a strong Board.

The Council recommends that BDS and area agencies consider incorporating requirements for best practices related to Board membership for non-profit organizations in the Board requirements. This may include consideration of term limits, requirements that Board members live in the area agency catchment area, racial and ethnic diversity of members, diversity of geographic region and diversity of disability. The Council strongly recommends that BDS adds a requirement that the Board must include at least one person with a disability who is

supported by that DADS entity as a full voting member of the Board, in addition to the requirement that 1/3 of the Board is made up of consumers as currently defined.

The Council supports the requirement that area agency Board members be trained in person centered thinking at start of membership. We recommend that BDS develop a list of approved person-centered trainings for Boards of Directors and are willing to assist with developing this list.

In the section regarding the Executive Director, the Council recommends that the Area Agency Executive Director is evaluated annually and in writing by the Board of Directors.

(p)(2)(d) Free from conflict

The Council strongly supports the addition of this provision to the rule.

Section (u) addresses the area agency plan. The Council recommends that the plan includes a regular (at least annual) report of actions taken and progress made to comply with conflict free case management requirements as required in He-M 503 for all agencies requesting an exception to conflict free case management requirements.

The Council recommends that the area agency plan is posted on the area agency website; that the area agency regularly updates progress on the goals in the plan and this is also published.

The Council recommends that the rule requires regular meetings with people with disabilities who receive services, family members and other interested parties regarding plan development and progress.

In terms of Section y (eligibility), the Council will discuss the eligibility process at a future meeting to determine if a workgroup on eligibility may be helpful at some point in the future. No specific changes to this section are recommended at this time.

He-M 505.08 Redesignation

(f) Approval of an area agency's request for redesignation shall be granted if, based on the following information, the area agency is found to be in compliance with (e) (1)-(9) above:

(1) Public comments generated by forums with the board of directors, self-advocacy groups, and the family support council regarding the area agency's demonstrated ability to provide local services and supports to individuals and their families;

(2) A comprehensive self-assessment of the area agency's current abilities and past performance;

(3) Input from a wide range of people, agencies, or groups who are either recipients, providers, or people who collaborate in the provision of services and supports;

(4) Documentation pertaining to area agency operations available in the area and at the department; and

(5) Input from department staff who have direct contact with and knowledge of area agency operations.

The Council recommends that this section include more specifics about who is asked for input during the redesignation process. This should include a requirement that area agencies directly ask the following groups for input: People First of NH, NH Council on Developmental Disabilities, Disability Rights Center – NH, ABLE NH, local self-advocacy organizations, provider agencies and any statewide or local organizations who may provide useful feedback to improve area agency services.

We support the required community forums and encourage area agencies to host forums in person and via Zoom or other web-based meeting software to insure broad participation of people with disabilities and families and that these forums be recorded and made available.

Finally, the area agency must broadly distribute a survey to recipients of services, family members and others as an additional way of gathering feedback.

He-M 505.13 Waivers

The Council recommends that information about any current waivers be available on the area agency website. This could include all waiver received, trended data on specific rules waivers and information about efforts to come into compliance with the waiver rule.

Finally, depending on the rule being waived, waivers for five years seems too long. The Council recommends that BDS examine whether this duration is appropriate for all rules.

The Council also recommends that these recommendations be added to the new provider rule and to He-M 503 rules if appropriate.

Conclusion

In addition to the comments on specific sections of the rule above, the Council has several additional concerns. First, it is unclear in this document how the area agencies will be able to assist if a person with disabilities or family is dissatisfied with their services or if there are other issues with services in their region. If area agencies are suppose to address or rectify concerns, they must have the authority to do so. If not, BDS should be expected to make changes.

Second, the Council recommends that the state ensure that area agencies have sufficient funding to implement these recommendations if there are additional costs.

Finally, the Council is concerned about the amount of time allowed for informal feedback on rule changes of this magnitude. The Council requests that BDS commits to further discussion with the Council and all stakeholders in one year to address any unanticipated challenges with these changes.

Thank you for your consideration of these comments. Both the Rules and Regulations committee and the full Council are happy to meet to discuss these issues further if that would be helpful.

Sincerely,

A handwritten signature in black ink, appearing to read "Stephanie Patrick". The signature is fluid and cursive, with the first name and last name clearly distinguishable.

Stephanie Patrick, Chair

Isadora Rodriguez-Legendre, Vice Chair