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April 15, 2020

Ms. Kaarla Weston
Via Email: IHSWaiverRenewal@dhhs.nh.gov
NH Dept of Health and Human Services
Attn: IHS Waiver Renewal Input
105 Pleasant Street
Concord, NH 03301

Re: In Home Supports Waiver

Dear Kaarla,

On behalf of the NH Developmental Services Quality Council, we submit the following comments on the In Home Supports waiver application. The NH Developmental Services Quality Council was created by the NH legislature "to provide leadership for consistent, systemic review and improvement of the quality of the developmental disability and acquired brain disorder services provided within New Hampshire's developmental services system" (RSA 171:A:33).

First, thank you for all your work on the In Home Supports (IHS) waiver draft. The IHS waiver is a critical support for families of children and young adults with developmental disabilities across the state.

Overall, the Quality Council is pleased with a number of the changes in the waiver including the additional services added, expansion of options for family support with the Participant Managed and Directed Services (PDMS) function of the program, increased caps for services and development of a PDMS committee to help the Department to consider and meet the needs of families using this service. The Council is also pleased with the replacement of Enhanced Personal Care with In Home Residential Habilitation which will provide increased flexibility in the services provided by direct support workers.

Enclosed are the comments that the Quality Council submitted in the public comment session prior to the release of the draft waiver. Outlined below are some concerns carried over from the previous comments and some additional concerns.

1. The maximum budget available under the waiver may be too low.

The Council appreciates that the maximum budget was increased from \$30,000 to \$35,000 but believes this cap may still be too low to meet the needs of some families. According to waiver documents, the average cost to serve one child in an ICF/DD (Cedarcrest) is approximately \$180,000 more than the maximum budget available to a child on the IHS waiver. Even with the increase, the cap may not be

sufficient to meet the needs of children with the highest level of need in their own homes and communities. There's still no explanation in the waiver or to the Council about how the \$30,000 cap or \$35,000 cap was developed except that it's less than institutional services.

The Quality Council recommends the Bureau look at the experiences of families who are at or near the cap budget for this waiver and consider an exception to the budget cap to allow additional funding in certain circumstances when needed.

2. Transparency in the administration of the waiver and oversight of area agencies is critical.

In the waiver application, the state outlines its oversight of Area Agencies in Appendix A, Item 6, Assessment Methods and Frequency. Over the past two years, the Quality Council has made repeated requests to the Bureau of Developmental Services for additional transparency in the assessment of area agencies, which the Bureau has consistently refused to provide. Currently, the state will only provide limited information about its assessment of the quality of area agency services at redesignation or once every 5 years. The state must be transparent about the results of the annual quality review process and Governance Desk Audit to the Quality Council and other stakeholder. The annual service file review results, provided to the Bureau of Developmental Services, annually, must also be provided to stakeholders upon request, promptly.

3. The state must take steps to ensure families can access independent case management and that all case managers are held to the same high standards to serve families.

We are pleased that families will have the ability to choose an independent case manager and it is important that expectations for both Area Agency and independent case managers are high. If a case manager is not meeting the needs of the family or otherwise not performing his/her duties, the case manager should be held accountable.

4. The cap on fencing is too low. The state must allow for exceptions to the cap in certain circumstances when necessary to keep the child safe.

The current cap of \$2500 for fencing is likely reasonable for most families. However, some children are at risk of running or other safety issues and may need a fence that is more expensive to stay safe. The state should allow for an exception to the cap as outlined for other services in the waiver application.

5. The state must assess and take steps to reduce or streamline documentation requirement to reduce the administrative burden on families.

There is an expectation that progress notes will be written at a minimum, monthly and will be submitted in a timely manner. Progress notes are an important record of care for the child, but the state must consider administration burden on AAs and families in implementing these and other standards. As the state improves Medicaid technology, it must consider a system that allows family and service coordinators to add notes directly to the record, see the status of the individual's budget live and on demand, provide the tools to allow families to actively manage HIS services.

6. The PDMS committee, as outlined in the waiver, must also ensure the voices of families are considered in waiver implementation.

As outlined in the waiver, the committee is responsible for defining the rights and responsibilities of families. The committee should also be tasked with the development of clear, family friendly documents outlining expectations of area agencies, service coordinators, and BDS. The committee should also address training needs and requirements including how family voices in can be incorporated in trainings for case managers and area agencies. As the committee is implemented, we believe it would be better to separate PDMS for children in the IHS waiver verses PDMS for adults in the DD and ABD waivers.

7. The waiver does not outline a process when funds are limited, and families must wait for services.

While the IHS waiver application indicates that the state does not limit the number of individuals served by the waiver, in actuality, the number of participants is limited to the funding authorized by the NH legislature. We hope that the legislature will continue to allocate sufficient funding each year to meet the needs of all eligible children. According to the most recent NH DHHS dashboard¹, there are currently 9 children waiting for the IHS waiver, down from a high of 94 in January 2017.

It is critical that the state outline procedures for managing a waiting list in the waiver document and ensure the list is administered consistently across the state.

Thank you for this opportunity to provide additional comments on the IHS waiver. We look forward to additional collaboration to improve the quality of services for adults and children with developmental disabilities.

Sincerely,

NH Developmental Services Quality Council

Sarah Aiken and Jonathan Routhier, Co-Chairs

Stephanie Patrick, Vice Chair

Cathy Spinney, Past Chair

¹ <https://www.dhhs.nh.gov/ocom/documents/november-2019-dashboard.pdf>