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February 10, 2021

Ms. Jessica Kennedy Via Email: [DLTSSWaiverRenewal@dhhs.nh.gov](mailto:DLTSSWaiverRenewal@dhhs.nh.gov)  
New Hampshire Department of Health and Human Services  
Attn: DD Waiver Renewal Input  
105 Pleasant Street Concord, NH 03301

Re: DD Waiver Renewal Recommendations

Ms. Kennedy,

The Quality Council appreciates the opportunity to comment on the Developmental Disabilities waiver (DD Waiver) which provides critical services to over 5000 adults with developmental disabilities and their families across the state.

As you may know, 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).

In July 2020, the Quality Council submitted comments regarding the DD waiver as part of the state's listening sessions prior to the release of the draft waiver. Those comments are provided in black italic below, with additional comments in blue.

We recognize that these comments include suggestions related to implementation of the waiver activities in addition to specific waiver requirements. Detailed comments are below.

Sincerely,



Sarah Aiken, Chair



Stephanie Patrick, Co-Chair

## Recommendations

### Additional Recommendations:

The waiver must prioritize opportunities for the person with the disability to lead decisions about his or her care, even if he or she has a legal guardian. For example, on Page 5, the waiver document indicates that individuals **and/or** their guardians work with area agencies and the state to identify necessary services and supports. We appreciate that legal guardians should be a part of the process but the person with the disability must be included. Similar statements are included throughout the waiver document and this must be corrected.

### Oversight/Transparency

1. *BDS must prioritize opportunities to not only gather input from families, stakeholders, and others to determine what is going well and what needs attention, but also share the results of the surveys with Quality Council, families, and other stakeholders. Transparency of the state's oversight is critical. Specific data to be shared include:*

- a. *Waiver quality reports to the Center for Medicare and Medicaid Services*
- b. *Annual governance desk audits for each Area Agency including:*
  - *Redacted results of family surveys and family focus groups*
- c. *Quality review of key indicators data*
- d. *Annual quality review process*
- e. *NCI surveys*

*Whenever possible, results should be published on the BDS website in an easy to find way within 30 days. In addition, BDS must respond promptly (within a few weeks) to specific requests for data from the Quality Council and other stakeholders.*

As noted in the original comments, transparency of the state's oversight of the waiver and performance of area agencies is critical. Once again, we encourage BDS to regularly share data regarding this performance with the Quality Council and outline specifics of this process in the waiver document. On Page 194 of the waiver, BDS references "regular discussions of quality initiatives" with a variety of stakeholders. This is not sufficient.

The Quality Council was established by the NH legislature via statute in 2009. According to RSA 171-A:33, "The council shall regularly review information on the quality of developmental services in New Hampshire and make recommendations for improving service quality and the quality assurance and continuous improvement systems, including but not limited to:

- (a) Standards of quality and performance expected of area agencies and provider agencies.
- (b) Types of data to be collected, analyzed, and disseminated to determine whether standards are being met.
- (c) Quality assurance and oversight mechanisms to be used to gather data and information.
- (d) Content, frequency, and recipients of quality evaluation and improvement reports.

- (e) Expectations and procedures for following up on identified areas where improvements are needed.
- (f) Structures, policies, rules, and practices, including staffing or organizational changes, to ensure that the developmental services system works as intended in RSA 171-A:1, including:
  - (1) Ways of supporting values-based and person-centered service planning and provision, as well as problem solving, innovation, and learning;
  - (2) Recognizing and disseminating what is working well (best/model practices); and
  - (3) Reviewing, interpreting, and disseminating data and information on a regular basis to bring about transparency for all stakeholders and the public.”

There is no reference in the waiver document of transparently sharing data with the public. The BDS website is difficult to navigate and the information regarding the quality of services provided is very hard to find. This must be addressed as it is critical to a healthy, well-functioning system. The Quality Council is currently exploring how to present existing data in an easy to understand way and would be happy to help with this initiative.

*2. Transparency of the state’s process to develop individual budgets to ensure statewide consistency in the development of individual budgets.*

We continue to encourage the state to provide additional transparency in the process to develop individual budgets. As noted above, a lack of transparency can only contribute to confusion and frustration for families and people with disabilities.

*3. The state should gather and regularly publish data on budget trends including analysis of budget data based on class, race, soci-economic status and other disparate or underserved groups.*

As noted above, there is no commitment to transparency of the budget process or to the publication of budget trends in the draft waiver.

*4. The state should develop more robust performance measures to measure the effectiveness of the waiver. As above, the results of performance measures should be published.*

We appreciate that the state has developed some more robust performance measures in the draft waiver and hope that the data around performance measures will be shared with stakeholders, including the Quality Council.

## Services

*5. All providers must comply with the HCBS settings rule. This is particularly critical for facilities with more than three beds. The state must minimize the exceptions to the rule.*

We continue to be concerned about the large size of authorized facilities/community residences (16 beds) and hope that the state will support the provision of services in independent apartments, family homes or other independent settings wherever possible. If a waiver participant must be served in a facility, the state must commit to actively decreasing the size of residential facilities and serving waiver participants in smaller facilities whenever possible.

We believe that facilities serve 4 or less people whenever possible.

6. *The state must make sure it and all providers/service coordinators are meeting the intent and substance of sub assurances in waiver regarding choice of provider (Appendix D:1: f).*

As noted above, we remain concerned that individuals are not educated about the choice of provider. We appreciate the additional detail in the draft waiver about how and when people with disabilities and family members will be informed. We hope that the state, area agencies and service coordinators ensure this education happens with all families.

7. *Throughout the waiver, the state should allow for and outline an individualized process to apply for an exception to the service limits in specific cases.*

We appreciate that most if not all services allow for the BDS Administrator to make exceptions to the cap. This flexibility will allow BDS to manage the costs of waiver services without denying critical services.

8. *Consider allowing the purchase of an already modified vehicle if less than the cost of modifications.*

This is not addressed in the draft waiver.

9. *The service array is not designed to address the specific needs of people with autism. The service array may need to be expanded to meet these needs. One example is ABA services for adults; another is employment check-ins that can be paid when they occur outside of working hours. Other gaps for this population are identified in the HB 4 report.*

Other than a mention of assistance with social support by employment service providers, it does not appear that the draft waiver addresses these needs.

As noted in the Governor's Commission on Disability's Analysis and Report by the Committee to Study the State's System of Support for Individuals with Developmental Disabilities and Recommendations for Reforms and Improvements issued in February 2020 (<https://www.nh.gov/disability/mediaroom/documents/hb4final.pdf>), the number of waiver participants with autism spectrum disorder is increasing and the lack of specialized services with evidence based outcomes for this population is a significant gap.

10. *The service array is not designed to meet the needs of people who are deaf and deaf/blind. Services do not support people who use alternate communication methods such as ASL or other signing.*

*Over the last year, BDS has made some commitment to the use of communication assessments and planning for waiver participants who face difficulties in communication. However, this commitment is not addressed in the waiver document.*

*The state must support and fund the Area Agencies and providers to assess the communication needs of the people they serve. We recommend the state collect data relative to this need and use said data to assess implementation of services.*

11. *Documentation is a significant burden and reduces time that can be spent on providing services. Inconsistent document requirements from different Area Agencies including in PDMS adds to the burden.*

Documentation requirements are not outlined in the waiver.

12. *Remove barriers in waiver and related rules, procedures etc. related to hiring staff quickly when possible. For example, consider relaxing rules around felony convictions.*

This is not addressed in the draft waiver. The waiver does not address specifics regarding the hiring of staff. The Quality Council encourages the state to address these barriers in rule and procedures.

13. *Consider adding non-medical transportation as a service to assist with employment, social activities or other activities as recently added to the CFI waiver. Consider creative solutions to address the transportation barriers faced by people with disabilities who want to work and participate in community activities including how waiver funding may be used to support a variety of non-medical transportation options to support multiple people with disabilities in a cost-effective way.*

We appreciate the addition of non-medical transportation as a service and the variable cap based on the need for specialized transportation for some individuals.

We are concerned that exceptions to the cap for this service are only allowable “when the cap must be exceeded to preserve the individual’s health or safety”. For all other services, the BDS Administrator has full discretion regarding exceptions to the cap. We are particularly concerned about this limit if an individual requires transportation to their job.

We are concerned that relying on “preservation of health or safety” is not appropriate. The services should be provided for maximum flexibility and independence and access to the community.

It is critical that expenses for parking, tolls and related expenses are included.

As this service is being implemented, we encourage the state to consider a variety of methods of provision to ensure cost effectiveness.

14. *Examine methods of supporting employment of people with developmental disabilities to ensure NH is providing innovative employment services including customized employment, natural supports in employment.*

The description of “employment consultant” service in the draft waiver is very similar to the description in the current waiver. We continue to encourage BDS to utilize innovative and evidence based employment support for people with developmental disabilities.

15. *Add specific performance measures related to employment outcomes, including rates of employment, wages, and hours worked for BDS in the waiver and for providers of employment services and area agencies more generally.*

As noted in early sections, we continue to encourage BDS to track employment outcomes for employment service providers and Area Agencies as a way to identify opportunities for improvement. Employment is a critical part of community integration for many people with disabilities.

#### Additional Comments

The draft waiver caps respite at 20% of the total budget for PDMS participants. This cap is not included in the current waiver. While we appreciate that the draft waiver articulates that training expenses do not count toward the 20% cap, we are concerned. As BDS knows, PDMS families are often forced to use respite funds to hire Direct Support Workers because of delays in the hiring process outside of their control. With the shortage of workers in NH, it seems unlikely that this will improve in the near future. If this cap is to remain, BDS must address delays in the hiring process.

## Case Management/Support Coordination

16. *Increase protections to ensure person centered planning or similar planning is designed to focus on the needs, wants and desires of the person with the disability first. Throughout the document, BDS must take steps to maximize and strengthen the ability of the person with disabilities to plan his or her life.*

The Quality Council continues to be concerned about whether person centered planning is fully implemented in the development of individual service plans. The Quality Council would like to see data regarding the implementation of person centered planning across the state.

We encourage BDS to support service coordinators statewide through training and best practices for person centered planning and to educate people with disabilities and families about a robust person centered planning process.

17. *The state must assure that person-centered planning maximizes the decision making of the individual with developmental disabilities, as outlined in Appendix D is actually used in developing the plan of care for all participants and the related assurances are met in all plans.*

See above.

18. *The procedures to remove a case manager does not respect the choice of the person with a developmental disability. If a case manager must be removed, the person with a developmental disability should choose the case manager and/or case management agency.*

This issue is not corrected in the draft waiver. On Page 65, the process for removing a service coordinator is outlined. In it, the area agency is responsible for designating a new service coordinator, with input from the individual and guardian and/or other supporter. It is critical that the individual with support from the guardian if appropriate, selects the new case manager.

In addition, BDS must put procedures in place to ensure that Area Agencies are facilitating the selection of an independent case manager quickly if they are to be responsible for entering into agreements with independent case managers before they can begin providing and billing for case management services.

19. *Documentation is a significant burden and reduces time that can be spent on providing services. Inconsistent document requirements from different Area Agencies adds to the burden. Implement universal documentation across area agencies.*

### Additional Comments:

On Page 125 of the waiver, the state indicates that "Entities and/or individuals that have responsibility to monitor service plan implementation and participant health and welfare may not provide other direct waiver services to the participant" and designates service coordinators as the individuals/entities responsible for monitoring service plan implementation. In reality, the waiver indicates that the state plans to continue to allow conflicted case management, with service coordinators employed by Area Agencies who also provide direct services to the individual. This is also in conflict with the state's obligation to move to conflict free case management/service coordination as required by CMS. This conflict must be addressed.



## *Eligibility/Allocation of Resources*

20. *Flexibility is key. NH is in a crisis of direct support now and will likely face significant budget challenges over the next few years. The state must allow people with disabilities and families the flexibility to design services that meet their needs in a cost-effective way.*

We appreciate the additional services that have been added to the waiver and hope that service coordinators will be encouraged to support flexibility in the development of service plans after the new waiver is implemented.

21. *State must consider its obligations under RSA 171 regarding the allocation of waiver funding and the full funding of the waiver waiting list. The three areas of eligibility as outlined in RSA 171 were not intended to be ranked priorities. All categories are important. The waiver must make it clear that these are not ranked priorities.*

On Page 31, BDS indicates that there is no waiting list for the waiver. However, in reality, the waiver is not fully funded by the NH legislature each year and some people have to wait. The waiver should outline the process for managing a waiting list when the waiver is not fully funded.

22. *There are no procedures to assess changes in need that are not a crisis or to reassess total budget based on increased costs of services. There is no allowance for COLA within waiver funding.*

As noted above, over the past 5 years, the DD waiver has not been fully funded every year. This waiver should articulate a process for allocating waivers when full funding is not available. This should include how to identify the need for increases in waiver funding based on individual needs that do not meet the criteria for a crisis and allocate needed resources.

## *Participant Directed and Managed Services*

23. *Consider expanding provision of PDMS to allow for various levels of participant managed services as outlined in the In-Home Supports waiver draft.*

We appreciate that two types of PDMS services are described in the waiver. These two types of PDMS services with the addition of services fully managed by the area agency, provide for a variety of options to best meet the needs of the person with disabilities and their family.

24. *Families face significant difficulties in recruiting and hiring staff. Remove barriers in waiver and related rules, procedures etc. related to hiring staff quickly when possible. For example, consider relaxing rules around felony convictions.*

Barriers to the employment of staff and the general shortage of direct support staff are not addressed in the waiver. We continue to encourage BDS to proactively address the workforce shortage and barriers/delays in hiring staff, include implementation of revisions to the criminal background check process

25. *Documentation is a significant burden for families. In some Area Agencies, the documentation requirements are much less than others. BDS should assess documentation requirements across the state and minimize when possible.*

We appreciate the creation of the PDMS committee of families, service providers and others to identify opportunities for improvement in the PDMS waiver. We hope that BDS will look critically at the documentation requirements for PDMS participants as part of this committee.

## Complaints, Grievances and Appeals

26. *The waiver must specify that families have the right to complain and appeal most if not all decisions of the area agency that affect them as a family including, but not limited to eligibility, services offered, funding, and quality of services. The waiver must more clearly explain the process to make complaints, file grievances and appeal.*

Details regarding the right of individuals with disabilities and their families to complain and appeal most if not all decisions of the area agency are not included in the draft waiver. The draft waiver includes less details regarding complaints and appeals than included in the current waiver.

We hope that these comments will be considered as the state revises HeM 202.

27. *Definition of complaint should be expanded. Consider: A complaint is a concern, dissatisfaction, or dispute expressed through written or verbal communication or expressed through other means, such as assistive devices, regarding: care, supports and services, action or inaction of staff, department or agency requirement, regulation or policy or other circumstances affecting quality of care or quality of life, including allegations of rights of violations.*

As noted above, the definition of complaint is no longer included in the waiver document.

28. *The waiver should expand the provisions regarding access to independent advocacy. Families should be informed of all independent advocacy possibilities. Notification should occur yearly.*

This does not appear to be addressed in the draft waiver. It is critical that people with disabilities and families know how to access independent advocacy if needed.

29. *Complaint process must be available on all area agency and provider websites in an easy to understand way that includes timelines.*

The waiver does not address the availability of information about the complaint process. We hope that BDS will require area agencies and providers to make this information easily accessible as part of their contracts.

30. *Grievances and appeals process including the requirements for notices must comply with federal Medicaid laws.*

The draft waiver explains the state's compliance with state rules regarding notices, but these rules specifically limit when notices are required to be provided. We encourage the state to ensure notice requirements related to the denial or change of benefits or services comply with federal law in terms of both when they are to be provided and the substance of the notice itself.

We encourage the state to consider using current technology to make this process more efficient and clear.

## Additional comments

On Page 162, BDS is required to "Describe how training and/or information is provided to participants (and/or families or legal representatives, as appropriate) concerning protections from abuse, neglect, and exploitation, including how participants (and/or families or legal representatives, as appropriate) can notify appropriate authorities or entities when the participant may have experienced abuse, neglect or exploitation."



The current waiver described efforts to educate people with disabilities and families at conferences and training. It also describes the role of the BDS liaison to help to divert or diffuse situations which may lead to abuse or neglect.

These activities are missing from the draft waiver, which does not describe any proactive actions by BDS or the area agencies to train or inform individuals of these protections outside of required notifications that typically occur yearly. These types of standard notifications, typically occurring with the development of the Individual Service Plan, are not sufficient.

### *Restraint and Seclusion*

31. *Additional protections are needed regarding the use of restraints and seclusion. This section of the waiver is vague.*

This does not appear to be addressed in the draft waiver.

32. *The state must require that restraint or seclusion, as used in response to behaviors in a crisis situation, is last resort in a situation where the person with the developmental disabilities or other people are in danger.*

We remain concerned that the use of restraint and seclusion as outlined in the waiver and HeM 310 is too broad. We're pleased that this data is being tracked and hope that this will also lead to reductions in its use.

33. *The state must differentiate expectations regarding specific types of restraint: physical, mechanical, chemical, etc.*

This is not addressed in the draft waiver. We strongly encourage BDS to look carefully at the expectations regarding the use of restraint as outlined in HeM 310.

34. *When physical or chemical restraint is included in a service plan, all caregivers must be trained on its use and alternate interventions. There should be an expectation that service providers are actively working to reduce the use of restraint, identify triggers, assist the individual in developing alternate coping mechanisms as part of the service plan and ongoing interventions.*

This does not appear to be addressed in the draft waiver.

35. *The state must require use of alternate interventions prior to the use of restraint or seclusion in a crisis situation related to behavior.*

As noted above, we feel that this language could be strengthened in both the draft waiver and HeM 310.

36. *The state should require a communication assessment if restraint or seclusion use increases.*

As noted in an earlier section, the state does not appear to be maximizing the use of communication assessments. We believe that communications challenges can lead to challenging behaviors and encourage the state to assess for communication needs whenever a pattern of restraint or seclusion is noted.

37. *The state must track and report on the use of restraint and seclusion.*

We appreciate that the state is now tracking the use of restraint and seclusion via area agencies and providers. We hope that data will be transparent and made available to the Quality Council.

38. *The state must require notification of serious injury or death in restraint or seclusion to DHHS, AG, DRC.*

This does not appear to be addressed in the draft waiver.

39. *The use of restraint and seclusion should more closely mimic those outlined in RSA 126 U, which governs the use of restraint on children.*

This does not appear to be addressed in the draft waiver.

#### *Intensive Treatment Needs and Services*

40. *Additional detail regarding the use of risk assessments/behavior plans to limit the choices of individuals is needed.*

41. *The state should ensure that waiver services to individuals with intensive treatment needs are provided in a manner that respects the rights and promotes the inherent dignity of the individuals served and promotes their maximal involvement in community activity while balancing their right to be supported in ways that do not trigger challenging behaviors. It should also allow for treatment that is evidence-based and individualized; and are reviewed at a frequency which allows for timely modification of supports and services which matches the individual's progress.*

42. *Services for people with intensive needs are not well integrated in the waiver and there are sometimes gaps. The state must consider how the waiver can provide the specialized services to meet the needs of this population that may be different from other waiver participants. Consider the recommendations from the SB 86 and HB 4 reports in this area.*

43. *The service planning process and determinations of service provision for people in the ITS system must outline the right of the person with a developmental disability or family member to appeal.*

*We acknowledge that this right is extended to all participants of waived services as described in the draft waiver.*

44. *The standards for crisis response services providers should be more clearly defined including expertise in de-escalation or other tools to meet the needs of the individual with developmental disabilities in a crisis. Consider the expectations for mobile crisis providers as a model. Consider the recommendations from the SB 86 and HB 4 reports in this area.*

*While this is not specifically articulated in the draft waiver we continue to encourage the state to integrate the findings and recommendations from SB 86 and HB 4.*

#### *Other*

45. *Consider lessons learned in addressing the COVID-19 pandemic to provide services in different ways.*

a. *Telehealth/teleservices*

b. *Remote provision of services*

c. *Use of remote supports*

d. *Virtual check ins that may be more frequent and/or less invasive*

We appreciate the addition of remote service provision throughout the document. Many people with developmental disabilities have benefited from the use of remote services via the Appendix K.

There must be parity in rates for remote services and audio only must be allowed when individuals with disabilities do not have access to video or video is not appropriate.

46. *Training should be given more attention. The state must actively measure the outcomes of training including by method to ensure trainings are actually resulting in improved quality of services. Families report that they prefer in person training and that it is the most effective training method.*

We did not find evidence of increased expectations for training in the draft waiver. We encourage BDS to actively engage families and the Quality Council in the development of training expectations and modules.

47. *Families need tools to help them understand waiver processes and their rights in easy to understand ways.*

See above. We believe that increased training for families, provided in a variety of formats, can better help families understand their rights and how to advocate for the services that they need.

48. *The state must ensure the Area Agencies provide culturally competent services, including services to people who speak limited English, racially and ethnically competent services, diversity in disability, and services that respect the gender identity and sexual orientation of waiver participants. The waiver should support these efforts and barriers must be addressed. The state should consider a performance measure in the waiver in this area.*

We are disappointed that there is no mention of cultural competency in the waiver document. We continue to believe that it's critical that BDS and the area agencies activity support efforts to ensure culturally competent services for all waiver participants.

Information should be available in multiple languages for both waiver participants and service providers/employees.