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

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 disabilities across the state. These comments outline a number of concerns with accessing services across the state.

Some of these concerns may be addressed via changes to the waiver. Others may require regulatory changes, changes in law or changes in practice. The Quality Council is taking this opportunity to provide a summary of these concerns and urges the Bureau of Developmental Services to take action on these via the draft waiver or by other means.

In addition to these comments, the Council encourages BDS to consider the issues outlined in the Report of the Committee To Study the State's System of Support For Individuals with Developmental Disabilities and Recommendations for Reforms and Improvements, published in February 2020 (HB4 Report)

Following are waiver specific recommendations. At the end of the document, we are also including additional recommendations to improve the quality of the Developmental Disabilities service system which may not be able to be addressed specifically in the waiver renewal document.

## RECOMMENDATIONS

### 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.

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

### Services

5. All providers must comply with HCBS settings rule. This is particularly critical for facilities with more than three beds. The state must minimize the exceptions to the rule.
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).
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.
8. Consider allowing the purchase of an already modified vehicle if less than the cost of modifications.

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.
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.
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.
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.
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.
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.
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.

#### 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.
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.
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.

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.

#### 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.
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.
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.

#### 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.
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.
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.

#### 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.
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.

28. The waiver should expand the provisions regarding access to independent advocacy. Families should be informed of all independent advocacy possibilities including DRC-NH, ABLE-NH and others. Notification should occur yearly.
29. Complaint process must be available on all area agency and provider websites in an easy to understand way that includes timelines.
30. Grievances and appeals process including the requirements for notices must comply with federal Medicaid laws.

### Restraint and Seclusion

31. Additional protections are needed regarding the use of restraints and seclusion. This section of the waiver is vague.
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.
33. The state must differentiate expectations regarding specific types of restraint: physical, mechanical, chemical, etc. This should include when each type may be used, when it can be included in a service plan, etc.
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.
35. The state must require use of alternate interventions prior to the use of restraint or seclusion in a crisis situation related to behavior.
36. The state should require a communication assessment if restraint or seclusion use increases.
37. The state must track and report on the use of restraint and seclusion.
38. The state must require notification of serious injury or death in restraint or seclusion to DHHS, AG, DRC.
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.

### 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; promotes their maximal involvement in community activity while balancing their right to be supported in ways that do not trigger challenging behaviors; allows 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.
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.

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

## **Additional Recommendations to Improve the Quality of the Developmental Disabilities Service System**

### Oversight and Transparency

49. Data is not integrated. Each area agency has its own system, meaning it is difficult to compare between area agencies and identify trends across regions.

### Services

50. Waiver should maximize opportunities for participants to work and remain eligible for waiver services.
51. Supported employment services should be expanded and incorporate best practices in employment for people with developmental disabilities.
52. Employment providers should be held accountable for meeting employment outcomes and utilizing the best method for the individual to do so.
53. Consider whether the restrictions on hiring someone with a criminal conviction are reasonable and modify if not.

### Participant Directed and Managed Services

54. Incorporate processes for holding fiscal management providers in PDMS accountable for the quality of services they are providing including expected timelines for activities. Area agencies must be held accountable so that families do not lose potential workers due to delays.
55. PDMS families must have access to crisis and emergency support so burden does not fall entirely on families.
56. Families must not be required to use PDMS because they cannot otherwise find and retain quality staff.

### Complaints, Grievances and Appeals

57. Families need centralized information about complaints, grievances and appeals including how to make a complaint, grievance, or appeal; the differences in each method; timelines; and how to obtain assistance.
58. Funding for complaint investigations should not be the responsibility of Area Agencies.

### Other

59. 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.

60. The individual with developmental disability's right to relationships must be respected. Service providers and case managers must discuss relationships and sexuality with waiver participants and encourage the choice of the person with the developmental disability to actively engage in relationships if that is what they want.
61. Consider an independent ombudsman specifically for DD/ABD waiver to assist waiver participants and families in navigating the system and advocating for themselves.