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May 21, 2025

Jessica Gorton, Bureau Chief
Bureau of Developmental Services
Main Building, 105 Pleasant Street
Concord NH 03301

Re: Participant Directed and Managed Services

Dear Bureau Chief Gorton,

This letter and recommendations were reviewed and approved by the full Council on May 21, 2025.

Over a period of 6 months, the Rules Committee of the Quality Council met to discuss Participant Directed and Managed Services (PDMS) in preparation for comments on the HeM 525 rule renewal. During these meetings, it became clear that the Council should consider the challenges and opportunities within the PDMS system more broadly before developing comments on the specifics of the HeM 525 rule.

In April 2025, the Council recognized it must consider additional input from people with disabilities and families and other interested parties as to their experiences. On April 11, 2025, the Rules committee hosted a listening session to gather this input.

The comments below were developed by the Rules committee using information from public listening sessions and a series of meetings regarding PDMS over 6 months.

Eight major themes emerged from the discussions. Below we explain each one of these in more detail. We follow with recommendations to improve the PDMS system including current activities which are important to maintain and additional solutions to address these issues.

We recognize the Bureau of Developmental Services' commitment to improving the PDMS and hope that this overview of the issues and recommendations will make the PDMS program better for all participants. We also recognize that the PDMS system cannot improve without a commitment to change from area agencies, service coordinators and provider agencies. We encourage BDS to share this letter with these agencies and work with them to implement needed changes.

1. Lack of transparency and accountability

Participants want to understand why decisions are made and who is responsible for decisions. They feel there is a diversion of responsibility (BDS, the area agency, the state, CMS) when situations are difficult. PDMS participants don't understand who is making these decisions or why. When participants question a policy or decision, they are told "BDS doesn't allow this" even when the provider or area agency is responsible for the restriction. There is little opportunity to access the waiver process, ask questions of those responsible for the decision or even explain how a decision may be impacting a participant in unexpected ways.

This includes provider and area agency decisions to require encryption on over email, limits on services, refusals to submit waiver requests or refusals to pay for certain services.

In addition, PDMS participants are not told that they can access other FMS providers that may be better able to meet their needs. When participants are told that "BDS doesn't allow this" they will reasonably assume that other providers will have the same restrictions which may not be true.

2. Lack of consistent and clear communication

PDMS participants and their families seem to have very different PDMS experiences and get different PDMS information in different regions. It is unclear why. Sometimes it seems that information is explained differently in different meetings or by different people.

Participants are also concerned that they receive inaccurate information from their area agency. One participant mentioned a letter from their area agency that had to be retracted later. This causes considerable stress and leads to much confusion among PDMS participants.

Communication becomes even more challenging when things change. Families struggle to get accurate information when service coordinators, area agencies and provider staff do not understand the changes or are not informed. Participants and families report that they are actively discouraged from reaching out to their BDS liaison.

Finally, service coordinators do not seem to be informed of some things in a timely way. It is unclear whether the information is not trickling down to service coordinators, or it is not being explained in the best ways. Many times, PDMS families feel like they are responsible for educating their service coordinators about the service delivery system.

3. Lack of uniformity among agencies

Area agencies seem to interpret rules differently in different regions. Some are strict, using very conservative interpretation of rules; others are more flexible. It is unclear if this is primarily due to different interpretations of rules and procedures or a lack of clear understanding by providers. This also leads to even more confusion about the different roles of the case manager, family and area agency, especially when rules or procedures change.

For example, reports are that some agencies are using a reimbursement model. This is not appropriate and can be a significant barrier to services for many participants.

Another example is the process for requesting and obtaining waivers. PDMS participants are not consistently given the option to request a waiver even when it seems appropriate.

Finally, many participants don't fully understand what services are offered in the waiver. Families are expected to "figure this out" and ask for a service if they need it. The Council recognized that waiver services funding is limited but believes strongly that waiver services must be individualized to meet the needs of participants and their families.

4. Isolation

Families shared that they often feel isolated and want better or more ways to connect with each other.

5. Flexibility

As the state considers changes to the PDMS program, maintaining a flexible system is the priority. The system must allow participants to make spontaneous decisions about what to do and where to go and to be allowed to change their mind. This includes:

- Flexibility in the selection of staff
- Flexibility in the selection of activities and schedule
- Ability to move at your own pace

Participants report that recent changes have caused a loss of previous program flexibility. This includes increased paperwork, an overreliance on connecting everything to a goal and requiring justification for everything.

Finally, we want to note that some families are using the PDMS model because the traditional model is not available, not because they want to use the PDMS model. They may struggle with implementing it and it may not meet their needs. The state must have a variety of service delivery options that are truly available.

6. Participant input

PDMS participants and their families are experts in how the PDMS program is going. BDS must create safe spaces to gather their information without fear of a negative impact on their services and BDS must use their feedback to make changes.

7. Clear process to ask questions and dispute decisions

As noted above, participants and families are not adequately informed about how and why decisions are made. When they ask questions, they are told that they can't contact their BDS liaison or their service coordinator refuses to help them to do so. In the waiver process and more broadly, participants are often told that "the state doesn't allow" this or that without any additional explanation including how to appeal. It also seems that service coordinators do not fully understand their obligations to follow Medicaid requirements regarding denial and reductions in services.

8. Hiring, onboarding and retaining employees

It is difficult to find direct care staff and delays in the hiring process can cause PDMS participants to lose staff who cannot afford to wait through a long hiring and onboarding process.

Families report that they must monitor every aspect of the hiring process to make sure it is progressing, requiring numerous calls to their provider or area agency each week. Generally, there are a lot of delays in the process for a variety of reasons that the PDMS participants cannot control. Forms are lost causing additional delays.

Once someone is hired, the required onboarding is also difficult and very time-consuming.

It is difficult to plan for emergencies if staff are not able to come to work. Families often serve as the emergency backup, but this is not always sustainable.

Finally, there is much confusion regarding changes to the requirement for TB testing.

<u>Recommendations</u>

The Council recommends that the state implements the changes below to address these challenges. As noted above, we recognize that the PDMS system cannot improve without a commitment to change from area agencies, service coordinators and provider agencies. We hope BDS will share this letter with these agencies and work with them to implement needed changes to the PDMS program.

1. Facilitate more communication among PDMS families. This could include a monthly newsletter, in person groups or informal networks.

2. Provide more training for families about different service options, their rights, the process to appeal decisions and other relevant topics. This also includes inviting families to attend provider trainings if they are interested.
3. Provide more training to service coordinators.
4. Developing more written guidance and sharing guidance broadly. When BDS implements statewide changes develop model letters to families that area agencies and providers can use to ensure consistent communication.
5. Develop:
    a. A list of services that are available in each waiver. Service coordinators could recommend or highlight specific services that might be appropriate, but families should be informed about all options.
    b. Templates for commonly used forms, letters, etc. This will help with consistency and is more efficient.
    c. FAQ on common issues like how to hire, how to terminate, required documentation, how to appeal decision; what to expect at various stages of the process.
    d. Charts about who is responsible for each item and who to call if things are not working like they should
    e. Rules, regulations and procedures in plain language.
6. Develop a hiring portal so that families can monitor the status of potential new hires.
7. Consider other PDMS models: Other states allow families to use a model where families have some input on schedules and activities but no oversight of employees. Others allow individual/family input in employee evaluation. There is a model where families are responsible for paying staff and families are reimbursed. As part of this, consider why the revised models in the last IHS waiver were not successful.
8. Increased rates so that families can recruit and hire the staff they need. Even with increased pay in PDMS, the hourly rate is not competitive and doesn't account for individuals with higher medical or behavioral needs.
9. Consider models of shared HR/benefits to decrease costs and allow PDMS participants to offer more/better benefits to employees.
10. Minimize burdens on families as much as possible including:
    a. Paperwork
    b. Legal responsibilities and risks

c. Emergency backup obligations

11. Maintain as much flexibility in the PDMS process as possible.
12. Liaisons should track of reported issues by AA to identify the need for more or different training for service coordinators or others. This will help to make sure information is passed down and trends are identified in a systematic and thorough way.
13. Develop resources to make sure participants, families and service coordinators offer alternatives when a service is denied including other insurance options, grant options. This should be required as Medicaid is the payor of last resort.
14. Encourage service coordinators to discuss the array of services available to develop individualized plans that meet the needs of the individual. The priority is not to develop plans that cost less.
15. Ensure service coordinators ask for services that people need and do not deny a service because they believe that BDS won't fund it.
16. Develop a process of assessment of appropriateness of PDMS for individuals.

Finally, the Council recommends more BDS oversight of the PDMS program. The Council believes that the program will be more effective for participants and families is BDS develops and require specific policies procedures, forms and communication with participants families. and make AAs follow them. Require that BDS approves broad communications with families before they go out.

Thank you for the consideration of these recommendations. We hope that you will provide an update in writing about progress on these recommendations by November 15, 2025.

Sincerely,

Emily Manire
Emily Manire
Quality Council Chair