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The In-Home Supports waiver is vital to families across New Hampshire. The Quality Council appreciates the value of the In-Home Supports (IHS) waiver for the over 500 children with disabilities served across the state. The waiver saves the state money and helps families remain together by reducing institutionalization. However, there are a number of challenges with the current implementation of the waiver, highlighted below.

1. Families are desperate for workers

New Hampshire is facing a crisis in direct support. With one of the lowest unemployment rates in the country, NH's families are struggling to attract and maintain qualified staff and there's been little discussion of creative solutions to address this crisis.

Families who are approved for the IHS waiver desperately need the support to keep their children out of institutions. Several families reported going without staff for a year or more, despite ongoing efforts to recruit staff. One family suggested that they be allowed to hire younger staff to provide the support. Others mentioned the desire to share staff with other families, without the budget implications (up to 32% in addition to the direct worker wage can be spent on benefits and other administration).

The background check and hiring process is slow. While participants are told they can manage and direct their own services, they are still limited in the rates of pay for staff. Many families are forced to supplement these rates to retain qualified employees. Some families do not have the resources to supplement and struggle to hire the staff they need.

Recommendations:

- Improve the process for hiring new staff, including the process to obtain background checks quickly. Assess the timeline for new staff to begin work and improve wherever possible. As part of this process, solicit feedback from families. Consider a developing a checklist to explain the process.
- Invest resources in the recruitment of direct support workers, including marketing. Consider recruiting at high schools and colleges, internships, and other creative solutions to find staff.
- Allow increased flexibility in the use of staff: sharing staff, flexible schedules.
- Remove the cap on hourly wages for direct care staff and let families decide how to use their budget.
- Consider increase flexibility for families to supplement the pay if they have the means to do so.

2. The waiver is not implemented consistently across the state.

The state has delegated much of the eligibility and implementation of the IHS waiver to local area agencies, which have inconsistent policies and procedures to administer the waiver and determine eligibility. In the IHS waiver application, the state outlines the eligibility for and services provided by the waiver. Areas of inconsistency reported by families include:

- Delays in the eligibility process
- Communication about the availability of the waiver for potentially eligible families varies based on region
- Restrictions and limits on the use of the waiver and waiver services

Part of the problem may be inconsistent messages from the BDS liaisons to the area agencies and service coordinators. The state must make efforts to provide consistent written messages to all area agencies and hold the area agencies accountable for consistent practices.

Recommendations:

- Ensure all 10 area agencies consistently follow the waiver guidelines and any supplemental guidance provided by the state regarding the services provided by the waiver and governing policies.
- The state must take steps to affirmatively monitor the administration of the waiver, including the determination of eligibility and hold area agencies and service providers accountable.
- The state must also ensure clear communication and consistent practices across the state regarding eligibility for the waiver and its availability to families.

3. Support from service coordinators is inconsistent.

Qualified, trained and knowledgeable service coordinators are critical piece of the IHS program. The state and its designee, the area agencies, must provide resources to ensure IHS service coordinators can operate to a high standard and ensure the quality of service coordination across the state.

Families reported that, in the past, service coordinators were trained and supported in a consistent way across the state and the Bureau of Developmental Services held regular meetings of service coordinators so that they could learn from their peers and information could be communicated consistently. It is unclear if these meetings are still happening.

Recommendations:

- Provide consistent available, regular training for service coordinators by AAs and outside independent groups.
- Incorporate family perspectives and experiences into trainings.
- Develop supplemental resources in writing to laws and rules to more clearly define expectations for service coordinators. Share these resources with families.

4. Expectations on families and service providers are not realistic.

The purpose of the In Home Supports waiver is “to provide personal care and other related supports and services to promote greater independence and skill development for a child, adolescent, or young adult who has a developmental disability and has significant medical or behavioral challenges as determined pursuant to He-M 524 that allow them to remain living at home with their family and actively engaged with their community.”¹

Often, parents do not receive the supports the need to develop meaningful and measurable goals for their children and ensure providers are helping their children to achieve these goals. Many case managers do not have the expertise to develop these goals and assess children’s progress. If the state expects waiver services to promote skill development and increase independent, plans must be individualized, and families must have access to skilled staff to help them to develop these goals and assess progress funded via the IHS waiver, Medicaid State Plan or by other means. The waiver must also properly fund direct services providers with the necessary expertise to implement these goals.

As discussed above, families struggle to find employees to provide support and they are encouraged to hire neighbors, friends, relatives. These employees and the families who are hiring them are very skilled with individual, but may not know how to implement specific goals, assess and document progress, or provide consistent data. If families are to be held to the expectation of demonstrating progress on meaningful and measurable goals, these employees and families need ongoing support.

Recommendations:

- Maintain flexibility in the waiver. Allow families to decide what resources best meet needs of their child. The waiver supports children with a wide variety of disabilities and needs so this flexibility is critical.
- If the expectation is that direct support staff and families implement and show progress on specific goals, provide ongoing access to experts for consultation to develop goals and assess progress (OT, PT, Speech, etc).²
- Identify and address barriers to accessing this expertise via Medicaid State plan services, the waiver or
- Funds for this consultation/training must not be taken from families already limited budgets.

5. Participation in the waiver requires the use of Participant Managed and Directed Services, which excludes some families.

While many families appreciate the ability to select and hire their own staff and pay a higher wage, this model does not meet the needs of all families.

¹ Application for 1915(c) HCBS Waiver: NH.0397.R03.01, Page 4. Available at <https://www.dhhs.nh.gov/dcbcs/bds/documents/ihs waiver.pdf>

² The Quality Council is very interested in better understanding the challenges faced by families in accessing these types of consultations and expertise from Medicaid State Plan and the waiver. We will explore this issue further at our meeting in Fe

- Families who are unable to direct and manage their own services, due to disability or for other reasons, are excluded from participation in the waiver. Many families report being overwhelmed by the requirements of PDMS and lack the proper supports to manage these services.
- PDMS limits the ability of families to coordinate the sharing staff between families, which is particularly critical in this waiver program where many families have only 10 hours of personal care support per week or less.
- Despite the fact that services are supposed to be managed and directed by families, many families reported that their ability to use the funds to meet their needs was limited.

In addition, the QC is concerned about the ability of children in the foster care system to access PDMS services, particularly the burden on foster parents to direct and manage services.

Recommendations:

- Allow flexibility in the waiver design to allow either agency directed, or participant directed and managed services to best meet needs of the family.
- Allow families to hire a facilitator with their funds to help them to manage and direct the program. Encourage all area agencies to provide this option.
- Increase flexibility in how funds are spent to allow families to purchase any service that Medicaid allows.

6. The cap on IHS services is \$30,000 per year and has not been raised since the waiver was established a decade ago.

The current IHS waiver document, available at <https://www.dhhs.nh.gov/dcbcs/bds/documents/ihs waiver.pdf> does not describe the process used by the state to determine the waiver cap; it only assures that the cost of waiver services is less than the cost of institutional care. Over the last decade, the cost of institutional services has increased, and it is critical that the state reassess the cap on the IHS waiver.

Recommendations:

- Increase the cap to reflect the real cost of services or delete the cap and fund services based on need to the maximum allowable. Consider the savings to the state in terms of institutional costs in determining the cap.
- If the cap is to be maintained or increased, be transparent in the process used to determine the cap.

7. Training needs are high and are training is not properly funded

Many families expressed concerns about both the cost and quality of training provided.

The costs of staff training, which can be up to \$1000 per staff members, is funded through the individual IHS waiver budget, subject to the \$30,000 cap. Some families can spend significant portions of their budget on staff training, particularly if there is turnover. This means that these families don't get the help that they need.

In addition, many families need staff who can provide skilled interventions. Neither the rates nor the training requirements support this level of skilled staff.

Finally, families need additional training on the waiver and its services so they can effectively advocate for themselves.

Recommendations:

The state must assess the current training structure including:

- State and area agency training requirements to add additional trainings to better serve families and remove unnecessary training
- Funding for training including the impact of training costs on the individual budget
- Method of training administration

In this assessment, the state must prioritize the impact on families. As noted above, family perspectives should be incorporated into trainings as much as possible.

8. The waiting list for services is administered inconsistently and is not properly detailed in the waiver application

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 dashboard³, 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.

Recommendations:

- Ensure any waiting list is administered consistently across the state. A family's region should not impact how quickly they can access the IHS waiver.
- Ensure consistency in reporting on the waiting list.
- As waiver funding is uncertain, it is likely that the state will have a waiting list for the waiver in the future. As such, the state must have a clear and consistent process for administering a waiting list across the state.

9. Coordination with the local educational authorities is poor

Most, if not all the children on the IHS waiver are also going to school and it is critical that the services are coordinated by both entities. Parents reported that they are often the intermediary between their child's school and IHS service providers, which can lead to gaps and inconsistencies. One parent reported that her child has two separate BCBA because one is funded by the school and the other by Medicaid. We must insure that children are receiving consistent messages from all their providers.

³ <https://www.dhhs.nh.gov/ocom/documents/november-2019-dashboard.pdf>

It is critical that the families, school officials, IHS staff and other providers work together to support the child with the disability. Interventions are most effective when messages are consistent.

Recommendations:

- Increase expectations for communication between schools, IHS providers and families.
- Area agencies and the state should actively work to help families when there are barriers or gaps.

10. The waiver and related policies are not designed to maximize community involvement.

It is critical that IHS services be provided in the community as much as possible. Many waiver services help to support community involvement, but there are additional opportunities. The waiver must be flexible and promote community activities. This may include creative transportation funding, allowing waiver funds to be used to pay for staff to attend events or activities with the child, etc.

Recommendation:

- Maximize flexibility in waiver design to meet the needs of individual families.

11. The respite limit is too low.

The waiver currently limits spending on respite to 15% of the budget. Families argued that this cap is too low, particularly when they are facing challenges in hiring personal care staff. In addition, it is unclear how the 15% limit is determined. Families also need a procedure to use respite funds while personal care staff are in the onboarding process.

Recommendations:

- Consider whether it's necessary to limit respite services at all considering the state must approve each family's budget.
- If it must be limited, examine why the limit was set and consider increasing the limit.
- If it must be limited, clarify how the limit is calculated.

12. The therapeutic recreation limit is too low.

The costs for therapeutic recreation have increased significantly and families cannot fund the services they need within waiver limits.

Recommendations:

- Consider whether it's necessary to limit therapeutic recreation services at all considering the state must approve each family's budget.
- If it must be limited, examine why the limit was set and consider increasing the limit.

13. Families fear losing their waiver budget.

At times, circumstances beyond the control of families cause allocated waiver funds to be left unspent as the end of the year approaches. Reasons include inability to hire direct support workers, hospitalization or even a change in family circumstances. Over the past several years, families have been told that they will lose their waiver funds if money is not spent. Sometimes, families feel pressure to spend waiver funds quickly to address this issue.

Families are often scared that their budget is reduced and their child's needs increase, they will not be able to obtain an increase.

Recommendations:

- Develop a clear process and guidelines about when budgets are reassessed. Insure that budgets are not reduced because families cannot find staff.
- When budgets are reduced, notify families of their right to appeal.