New Hampshire
NHDDQC
Developmental Services Quality Council

The Developmental Services Quality Council provides leadership for consistent, systemic review and improvement of the developmental disability and acquired brain disorder services provided within New Hampshire's developmental services system

Annual Report

October 2019 – September 2020

CONTENTS

HISTORY OF QUALITY COUNCIL

In 2009 the New Hampshire legislature passed, and Governor Lynch signed into law, HB 483 establishing the New Hampshire Developmental Services Quality Council (hereafter referred to as the Quality Council). The creation of the Quality Council came about as a result of the State Legislature's repeated consideration of issues affecting New Hampshire's developmental services system. In 2007 the New Hampshire Legislature passed SB 138 providing funding for the developmental services wait list, proposed increasing salaries for certain direct care workers, and establishing a broadly representative committee (known as the SB 138 Committee) to improve the capacity of New Hampshire's developmental services system to address workforce and quality assurance issues. In its final report, *SB 138 Quality Improvement Committee Report*, issued in November 2008 the committee recommended establishing, in statute, an ongoing council to review quality assurance efforts and make recommendations to improve the ability of the developmental services system to meet the needs and goals of the individuals it serves. The purpose of the Quality Council would be "to provide leadership for consistent, systemic review and improvement of the developmental disability and acquired brain disorder services provided within New Hampshire's developmental services system." (See Addendum #1 – *RSA 171-A:33*). By statute, the Quality Council is required to report to the New Hampshire Legislature. This is the Council's report; it covers the Quality Council's work from October 2019 through September 2020.

ORGANIZATIONAL STRUCTURE AND SUPPORT

In its first year, the Quality Council created an organizational structure and adopted by-laws. A subcommittee of the QC began to review the QC by-laws to ensure they were up to date. The by-laws call for the Quality Council to meet at least six times a year with an annual meeting in September. The meetings are open to the public and a period for public comment is included on every Council agenda. The Council's meeting schedule, agenda, and meeting minutes are posted on the Department of Health and Human Services (DHHS) website at http://www.dhhs.nh.gov/dcbcs/bds/qualitycouncil/

In accordance with its bylaws, the Quality Council has two elected offices, Chair and Vice-Chair. These seats were voted on at the September 2019 Meeting Sarah Aiken and Johnathan Routhier were again elected Co-Chairs and Stephanie Patrick was elected Vice Chair. Cathy Spinney will continue to remain on the executive committee as Immediate Past Chair.

During this reporting period, the Quality Council held regular monthly meetings beginning in January. However, the meeting in December was cancelled due to the holidays and the March meeting was cancelled due to the onset of the pandemic.

The Quality Council meetings were held at a Concord, NH location with Council members who were unable to travel to Concord having the option of participating in the meetings via teleconference or ZOOM. Starting in April, the Council transitioned to meeting fully virtually to comply with the nationwide emergency due to the COVID-19 pandemic.

Quality Council subcommittees during this reporting period included: Workforce/Employment, Transparency, Rules Review & Recommendations, Strategic Plan, and Executive. The Quality Council also got regular updates on the Living Well Quality Frameworks Grant and the Bureau of Developmental Services' Corrective Action Plan.

QUALITY COUNCIL MEMBERSHIP

The membership of the Quality Council as defined in the statute includes representation from the Bureau of Developmental Services; Area Agency Board of Directors; Family Support Councils; Institute on Disability; Brain Injury Association of New Hampshire; New Hampshire Council on Developmental Disabilities; Disability Rights Center; NH Council on Autism Spectrum Disorders; People First of New Hampshire; ABLE NH and Private Provider Network. The statute also calls for one direct support professional and one enhanced family care provider, appointed by the New Hampshire Council on Developmental Disabilities. At least 51% of the Council members shall be individuals served by the State's developmental system or parents of individuals who are served by the system.

The Quality Council has a committed and active membership. During this reporting period there has been a quorum at every Quality Council meeting. The amount of time volunteered, and the quality of professional experience and expertise provided by Council members has been exceptional. In addition to the monthly meetings, nearly all members serve on at least one Quality Council subcommittee. The membership list is regularly updated as representation changes. (See Addendum #2 – *New Hampshire Developmental Services Quality Council Members*)

While more than half of the Quality Council's active members are individuals with developmental disabilities or parents of individuals with disabilities, the Council has had difficulty maintaining consistent representation from these representatives. During this reporting period there was no identified representation from Enhanced Family Care Providers. The Quality Council has in the past struggled to fill all the seats from the Family Support Councils, Board of Directors. The Council's enabling legislation calls for three (3) representatives from local Family Support Councils appointed by the State Family Support Council and three (3) representatives from the Area Agency Board of Directors appointed by CSNI. During this reporting period there was one vacant seat for FS Councils and AA boards. The Quality Council continues to work on filling these seats.

QUALITY COUNCIL FOCUS AND PRIORITIES

By statute, the Quality Council is charged with reviewing rules to ensure that the state's developmental services system works as intended in RSA 171-A:1. To meet this obligation, the Council reviews all proposed changes in developmental services regulations. The Quality Council also tracks proposed legislation that could impact individuals with developmental disabilities and acquired brain disorders and their families and receives a legislative update at most meetings.

The Quality Council also reviews data from regularly issued and special governmental reports and makes recommendations as needed.

STRATEGIC PLAN

During this reporting period the Quality Council continued to make progress towards the goals outlined in the Strategic Plan. For each one, a Council member led the work on each goal. The leads for each goal worked to outline a timeline with steps necessary to complete the goal.

After March 2020, work on the strategic plan was delayed due to the COVID-19 pandemic and the need address on other priorities.

COVID-19 PANDEMIC

Due to the nationwide emergency due to the COVID-19 pandemic, the Council transitioned to hosting all meetings virtually. The Council heard updates on how the State was managing the pandemic by the member on the Council seated by DHHS and regularly discussed the impact of the COVID-19 pandemic on people with developmental disabilities and acquired brain disorders across New Hampshire.

PRESENTATIONS AND UPDATES PROVIDED TO THE QUALITY COUNCIL

The Quality Council had various presentations and updates throughout this reporting period.

CORRECTIVE ACTION PLAN UPDATES

The state of NH entered a corrective action plan (CAP) with the Center for Medicare & Medicaid Services (CMS) to address areas of non-compliance with Medicaid requirements including conflicts of interest in direct and case management services, direct billing, provider selection and rate development. The Bureau representative continued to update the Quality Council on this issue at each meeting. The Quality Council also has a seat on the CAP Stakeholder Advisory Group. The Quality Council consistently reviewed information and data pertaining the Corrective Action Plan, including information from the Stakeholder Advisory Group meetings and meetings of its subcommittees.

LIVING WELL QUALITY FRAMEWORK GRANT UPDATES

The Quality Council continued to receive monthly updates on the work of this grant through its second year. This included updates on grant activities from the Institute on Disabilities, Council on Developmental Disabilities, Disability Rights Center, ABLE NH, and CSNI. Grant activities included the developmental of a training for direct support professionals (DSPs) in how to support individual choice and leading a robust, inclusive, community-based life, led by people with disabilities and their families; management of critical incidences; reporting and tracking data; and the results of a survey of DSPs across the state.

COMMITTEES OF THE QUALITY COUNCIL

During this reporting period the Quality Council had 5 committees. Most committees meet regularly between the Quality Council meetings. Three committees were created to address issues of specific concern or interest to the Quality Council. These are Workforce/Employment, Transparency, and Rules Review and Recommendations. The final committees are the Executive Committee, created to plan meetings and address administrative/member concerns in between meetings and the Strategic Plan committee, created to support ongoing work on strategic plan initiatives.

WORKFORCE/EMPLOYMENT

The purpose of the workforce committee is to address issues related to Direct Support Professionals (DSPs), including the shortage of DSPs, the need for increased pay, and the lack of access to trained DSP's. During this reporting period, this committee was unable to meet regularly.

TRANSPARENCY

The Quality Council believes that for families and individuals to be able to make informed decisions about their supports and services, they need to have better access to information. The Council formed a Transparency Committee to improve accessibility to information and general transparency in New Hampshire's Developmental Services System. During last reporting period, the committee created a training for families and service coordinators to give a basic overview of the developmental disabilities system and services. During this reporting period, the committee made numerous attempts to schedule the training. However, DHHS would not move forward with it and the committee was concerned that the Department would not endorse the training if was provided by another organization. Because of these difficulties, the committee was unable to provide the planned training.

REVIEW OF RULES AND REGULATIONS

The Quality Council receives regular updates, typically from council membership, during the legislative session regarding the budget status and process, elections, and any relevant legislation.

The Quality Council reviews state developmental services regulations as they come up for renewal and recommends changes to ensure that the regulations retain their relevancy for the current service system.

In this reporting period, the committee reviewed various rules and made comments on the following waivers:

- In-Home Supports Waiver (See Addendum #3 – *QC Comments on the IHS Waiver Dated January 27, 2020,* and Addendum #4 – *Additional QC Comments on the IHS Waiver Dated April 15, 2020)*
- Developmental Disabilities (DD) Renewal (See Addendum #5 – *QC Comments on the DD Renewal Waiver Dated July 2020)*

IN SUMMARY

New Hampshire Developmental Services Quality Council continues to provide leadership for the review and improvement of New Hampshire’s services for individuals with developmental disabilities and acquired brain injuries. The Quality Council has a diverse and active membership; those serving on the Council have given their time and talents and are committed to helping New Hampshire provide the best possible services for individuals and their families.

ADDENDA

ADDENDUM #1 – RSA 171-A:33

Developmental Services Quality Council

Section 171-A:33

171-A:33 Developmental Services Quality Council Established; Membership; Duties. –
I. There is established the developmental services quality council 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. At least 51 percent of the members of the council shall be individuals with disabilities served by the system or parents of individuals served by the system. The members of the council shall be as follows:
(a) The commissioner of the department of health and human services, or designee.
(b) A representative of People First of New Hampshire, appointed by such organization.
(c) A representative of Advocates Building Lasting Equality in New Hampshire (ABLE NH), appointed by such organization.
(d) A representative of the New Hampshire council on autism spectrum disorders who shall be either the individual who has an autism spectrum disorder or the family member of a person who has an autism spectrum disorder, appointed by the council.
(e) A representative of the Brain Injury Association of New Hampshire, appointed by the association.
(f) Two representatives of the New Hampshire Developmental Disabilities Council, at least one of whom shall be a person with a developmental disability, appointed by the council.
(g) Three representatives of local Family Support Councils, appointed by the state Family Support Council.
(h) One direct support professional and one enhanced family care provider, appointed by the New Hampshire Developmental Disabilities Council.
(i) Three representatives of area agency boards of directors including at least 2 persons with a developmental disability or family members of such persons, appointed by the Community Support Network Incorporated.
(j) A representative of the Community Support Network Incorporated, appointed by such organization.
(k) A representative of the Private Provider Network, appointed by such organization.
(l) The director of the Institute on Disability, University of New Hampshire, or designee.
(m) A representative of the Disabilities Rights Center, appointed by the center.
II. The groups represented under paragraph I are encouraged to provide, according to their ability, the in-kind and other resources necessary for the council to succeed. The council may request information and analysis on quality from the department of health and human services, area agencies, and providers. The council shall have access to all non-confidential information on quality for services funded all or in part by public funds.
III. 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.
IV. The council shall make an annual report beginning on November 1, 2010 that includes its recommendations and an assessment of the actions taken in response to previous recommendations to the governor, the speaker of the house of representatives, the president of the senate, the members of the house committee on health, human services and elderly affairs and the members of the senate committee on health and human services.
V. The meetings shall be convened by the commissioner of the department of health and human services, or designee, and shall meet regularly as determined by the council. The meetings shall be open to the public and subject to the provisions of RSA 91-A, the right-to-know law. The council may establish bylaws for governing its meetings, decisions, and other operations.

Source. 2009, 104:1, eff. Aug. 14, 2009. 2014, 102:1, eff. Aug. 10, 2014.

Agency/Organization	Representative	Contact Information
NH Department of Health & Human Services Bureau of Developmental Services 105 Pleasant Street, Concord, NH 03301 **Term Expires: 9/2020** *Nominating entity = LTSS Director*	**Sandy Hunt,** Bureau Chief, BDS Bureau of Developmental Services	sandy.hunt@dhhs.state.nh.us
People First of NH 4 Park Street #214 Concord, NH 03301 **Term Expires: 09/2020** *Nominating entity = People First of NH*	**Tammy Mills** **Alternate: Chrystal Johnson**	Tmills03781@yahoo.com (603) 675-2254 (603) 527-2684 (603) 393-1286
Advocates Building Lasting Equality in NH 2 ½ Beacon Street Concord, NH 03301 **Term Expires: 9/2020** *Nominating entity = ABLE NH*	**Lisa Beaudoin (Chair – Workforce, Employment)** Executive Director ABLE NH	lisa@herbanlivingfarm.org lisa.ablenh@gmail.com
NH Council on Autism Spectrum Disorders 2 ½ Beacon Street Concord, NH 03301 **Term Expires: 9/2020** *Nominating entity = NH Council on ASD*	**Adrienne Evans (Chair – Transparency)** Co-Chair NH Council on Autism Spectrum Disorders	adrienneferro@comcast.net
Brain Injury Association of NH 52 Pleasant Street Concord, NH 03301 **Term Expires 9/2020** *Nominating Entity = BIA of NH*	**Sandrine Iyizire**	sandrine@bianh.org

Direct Support Provider NH Council on Developmental Disabilities 2 ½ Beacon Street, Suite 10 Concord, NH 03301 **Term Expires: 09/2021** *Nominating entity = NH Council on DD*	**Debra Orman**	Deborlyn61@gmail.com
Enhanced Family Care Provider NH Council on Developmental Disabilities 2 ½ Beacon Street, Suite 10 Concord, NH 03301 **Term Expires: 09/2021** *Nominating entity = NH Council on DD*	**VACANT**	
NH Council on Developmental Disabilities 2 ½ Beacon Street, Suite 10 Concord, NH 03301 **Term Expires 9/2021** *Nominating Entity: NH Council on DD*	**Isadora-Rodriguez-Legendre** Executive Director NH Council on DD **James C. Piet, MS** Public Relations Specialist New Hampshire Department of Education, Vocational Rehabilitation	Isadora.Rodriguez-Legendre@ddc.nh.gov James.Piet@doe.nh.gov Phone: (603) 271-6894
NH Family Support Councils Bureau of Family Centered Services 97 Pleasant Street, Thayer Building Concord, NH 03301 **Term Expires 9/2021** *Nominating Entity = State FS Council*	**Debra Opramolla Region 5** **Karen Blake Mosman Region 1** **VACANT** **Alternate: Laurie Giguere-Thomas Region 10**	dopramolla@gmail.com kblake4213@gmail.com lgiguere@comcast.net

Area Agency Board of Director Members Community Support Network INC (CSNI) 10 Ferry Street, Suite 401 Concord, NH 03301 **Term Expires 9/2021** *Nominating Entity = CSNI*	**Cathy Spinney** **(Immediate Past Council Chair)** REGION 10 **Sarah Aiken (Council Co-Chair)** Region 4 **VACANT**	cspinney58@gmail.com (603) 635-9014 saiken@communitybridgesnh.org (603) 724-7039
Community Support Network INC (CSNI) 10 Ferry Street, Suite 401 Concord, NH 03301 **Term Expires: 09/2020** *Nominating entity = CSNI*	**Jonathan Routhier (Council Co-Chair and Chair – Strategic Plan)** Executive Director Community Support Network INC (CSNI) Alternate: **Heather Young**	jrouthier@csni.org hyoung@csni.org
Private Provider Network (PPN) 55 South Commercial Street 4th Floor Manchester, NH 03101 **Term Expires: 9/2021** *Nominating entity =PPN Board Chair*	**Emily Manire** Nashua Center 18 Simon Street Nashua, NH 03060	emanire@nashuacenter.org (603) 883-6163
Institute on Disability 67 Regional Drive #8 Concord, NH 03301 **Term Expires: 9/2021** *Nominating entity = IOD Associate Director*	**Linda Bimbo** Institute on Disability **Alternate: Mary St. Jacques**	linda.bimbo@unh.edu Mary.stjacques@unh.edu (603) 228-2084

Disabilities Right Center 64 N. Main Street #2 Concord NH 03301 **Term Expires: 9/2021** *Nominating entity = DRC Director*	**Stephanie Patrick (Council Vice Chair and Chair – Review of Rules and Regulations)** Executive Director Disabilities Rights Center	stephaniep@drcnh.org (603) 228-0432 Ext. 115

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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.

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[1] Application for 1915(c) HCBS Waiver: NH.0397.R03.01, Page 4. Available at https://www.dhhs.nh.gov/dcbcs/bds/documents/ihswaiver.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/ihswaiver.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 dashboard[3], 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.

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[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.

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Sarah Aiken, Co-Chair
Area Agency Board Member

Jonathan Routhier, Co-Chair
Community Support Network, Inc

Stephanie Patrick, Vice-Chair
Disability Rights Center

Members

Lisa Beaudoin
ABLE New Hampshire

Karen Blake
Family Support Council Member

Adrienne Evans
NH Council on ASD Member

Emily Manire
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April 15, 2020

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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. <u>The maximum budget available under the waiver may be too low.</u>

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. <u>The PDMS committee, as outlined in the waiver, must also ensure the voices of families are considered in waiver implementation.</u>

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. <u>The waiver does not outline a process when funds are limited, and families must wait for services.</u>

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 dashboard[1], 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

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

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Developmental Services Quality Council

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Area Agency Board Member

Jonathan Routhier, Co-Chair
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July 2020

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

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.