

May 23, 2022

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Bureau Chief, Bureau of Developmental Services
NH Department of Health and Human Services
105 Pleasant Street
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Re: Concerns regarding BDS Systems Redesign

Dear Director Hardy and Bureau Chief Hunt-Feroz,

We write to you today to express concerns with the Bureau of Developmental Services Systems Redesign process. As individual organizations, we've reached out to leaders at the DHHS to express many of these concerns at committee meetings, information sessions and in writing. Today, we are coming together to express our concerns and the gravity of the potential impact of these redesign efforts on an already fragile system of supports for people with developmental disabilities across New Hampshire.

Before we share our concerns, we want to acknowledge the commitment of the staff of the Bureau of Developmental Services and DHHS more broadly. We do not doubt that we share the same goals to create a system of services that supports people with disabilities to live the lives that they want to live as a part of their communities. The system of services is strongest when we all work together in a way that values all our different perspectives.

We recognize that there is much room for improvement in the developmental services system. People with disabilities and their families across the state are struggling to find providers, direct support professionals, home health aides, nurses, and other community-based supports. Many people with disabilities have sufficient budgets but cannot use their hours without these supports. In most cases, family members have stepped up to fill this void - they are exhausted, and some are enduring unsustainable economic hardship. People with disabilities, like other adults, want to live independently and cannot create their own independent lives when they do not have supports to live independently. The list of challenges in the current system is significant.

We also recognize that there are some good parts to the systems redesign. We strongly support efforts to:

- Modernize the IT systems to create more efficient and effective work processes including ways to measure systems success.
- Serve people with developmental disabilities in New Hampshire, rather than out of state with the proper infrastructure, funding, and staffing.
- Professionalize direct support professionals so that direct support is a career with livable wages and not just a job, that recognizes the dedication of our current direct support professionals and creates a system to attract more people to this field.
- Develop rates that support our current providers and bring more providers to the state.
- Ensure services are provided consistently and fairly across the state.

However, we have several concerns regarding the current plan that is being implemented that are outlined below.

- Family involvement - The lack of involvement of families during the redesign process from the beginning, and a lack of ongoing education to families regarding the changes the system will undergo and the way those changes will impact families is very concerning. Families must be provided with opportunities to share meaningful input throughout the process. When families do provide input, the state must listen and respond to their concerns, including why they cannot or will not be addressed in the redesign process.
- Scope of change - The state is in the process of implementing changes to rate methodology, direct pay, conflict-free case management, and its modernization. We believe that these changes may yield some of the goals of the larger systems redesign. The additional changes are premature and will overwhelm families.
- Diversity - It does not appear that DHHS is actively seeking to include the perspectives of the Black Indigenous, and People of Color (BIPOC) community (e.g., representation on committees), in this process or addressing these needs within the "systems redesign". Members of the BIPOC community, particularly those with limited English proficiency, immigrants and refugees experience unique challenges in accessing critical services and their voices must be included.
- Funding uncertainties - We appreciate the commitment to examine rates and increase as needed. However, we do not understand how the state can afford these increases without cutting services or increasing the budget for developmental services. Please explain how DHHS plans to fund these rate increases. If additional funding will be required, what is the state's plan to obtain

the funding from the legislature? What will happen if the legislature does not agree to these increases?

- Area agency stability - We are concerned that proposed changes to funding will impact the ability of area agencies to continue to serve the needs of people with disabilities and families in their region, particularly in crisis situations and as the provider of last resort. Ideally, area agency Board of Directors are made up of users of the system who truly understand the challenges facing people with disabilities and families in their regions. When this is happening as intended, this “bottom-up” decision-making authority makes our system stronger.
- Family Responsibility - Many families of people with developmental disabilities are providing significant direct support and care now because direct support workers are not available or their current waiver budgets are not adequate to meet their needs. Families are concerned that they will be asked or required to do more. There is no delivery system in NH without the FREE care offered by families. By necessity, the positions of those who offer a lifetime of this care cannot be ignored or minimized. Please reassure families that you do not expect them to provide even more FREE care; that their current number of staffed/paid hours will not be reduced without their consent to cover funding shortages/ rate increases; and/or that their current budgets will be proportionately increased to cover any DSP wage/benefit increases so that their number of staffed hours will not be reduced.
- Family Voices - It is critical that the state maintains support for the voices of people with disabilities and families in directing how their services are provided and how the organizations that serve them are run. BDS must commit to proactively strengthening and reinforcing the voices of families in the service delivery, including in the redesign process, other state led initiatives and as members of the Area Agency Boards of Directors.
- Stakeholder committee membership - While we appreciate that stakeholder committees are a part of the process, we have concerns about the structure of the committees and the expectations placed on those individuals who represent a variety of different interests. While members may serve on various groups and coalitions, they have not been appointed by those groups or authorized to speak for them. Each member brings their own experiences and perspectives to this process. It is not realistic to expect that members will go back to their groups and organizations to represent all of their committees and councils and the needs of their family at one time in a monthly two-hour meeting. In addition, it is not reasonable to expect them to share what is happening without also sharing their concerns about the process. There is also a concern that these committees are

structured in a way that does not give members the ability to truly recommend change. Many members have reported that they feel they are not able to truly make recommendations. It is critical to involve families that do not have a conflict of interest.

- Committee authority – Messages from DHHS have not been clear. It is critical that DHHS listens to the recommendations that the committees are making. What is the authority and decision-making power of each committee and work group in the redesign process?
- Reliance on residential/institutional care- Families of those with high support needs are concerned about the two proposed waivers, particularly that one waiver is “residential”. What does this mean for people with significant needs who do not want or need to live in a residential/institutional facility? Families are worried that, unless they agree to provide even more UNPAID supports, their loved one will end up in residential placement that is not wanted. It is critical that the state supports people with disabilities to live in their own homes and communities, even if they need 24 hour paid supports if that is their choice. This option MUST be stated in the language of one of the Waivers.
- System Needs- People with disabilities and families across the state clearly understand where the system is broken. We are genuinely concerned that a “systems redesign” is not addressing these clear needs. We are concerned that BDS chose to move forward with A&M’s recommendation of a 2-waiver system without any input from constituents.
- Use of the Supports Intensity Scale (SIS) - The state has indicated that the SIS will be used to develop budgets and we are concerned. Please explain how the state will ensure it is administered consistently and how results will be used.
- Limitations of the SIS - It is critical that the State consider the goals, hopes and dreams of those that we serve, and the SIS alone does not adequately focus on these goals. RSA:171A indicates that “Habilitation” is a primary responsibility of the system. The SIS does little to address this area. Nor does it adequately address defining the level of UNPAID supports the individual relies on currently or in the future to facilitate proper planning.
- Mixed messaging - Many stakeholders, including people with disabilities, have asked questions about the systems redesign process by mail, email and at the informational sessions. Specific questions regarding concerns are asked and general answers are received, answers are not clear, and are sometimes inconsistent. For example, families have asked about potential caps on budgets or specific services in the two waivers. The A&M Phase 1 report assumes caps

on services (<https://www.dhhs.nh.gov/ocom/documents/dhhs-operations-assessment-phase-1a-report.pdf>, Page 32). The current FAQ acknowledges this question, but does not answer it

(<https://www.dhhs.nh.gov/dcbcs/bds/documents/bdssystemworkfaqs.pdf>,

Question 9). Individuals have also asked this question at committee meetings and other planning meetings. The question: "Will this initiative include caps on budgets or services?" is clear - direct answers are yes, no or we don't know yet. Other answers and similar answers to other questions create uncertainty and confusion and can foster mistrust.

- Transparency - We appreciate that BDS recently uploaded videos of committee meetings from December, January and March to its website and expect that this will continue. However, we remain concerned about the number of decisions that have already been made without input from the various committees and inconsistencies in how the work of work groups is being reported. The lack of transparency continues to contribute to a lack of trust in the process.

We understand that this redesign cannot address all the problems facing people with developmental disabilities across the state. However, we anticipate continued problems if the state does not commit to addressing the real problems facing people with developmental disabilities each day: housing, transportation, and workforce shortages. These issues are all connected. DHHS must commit to actively working to address these issues to create a system that meets the needs of people with disabilities.

Please respond to these concerns in writing by June 10, 2022. We would also like an opportunity to meet about these concerns via Zoom. Please reach out to Stephanie Patrick and Carrie Duran.

Sincerely,

ABLE NH (Advocates Building Lasting Equality in NH)
Community Crossroads
Community Support Network, Inc.
Developmental Services Quality Council
Disability Rights Center - NH
Gateways Community Services
Granite Case Management, LLC
Granite State Independent Living
Great Bay Services, Inc.
Lakes Region Community Services
Monadnock Developmental Services
Monadnock Family Council

New Hampshire Council on Autism Spectrum Disorders
NH Council for Youths with Chronic Conditions (CYCC)
NH Council on Developmental Disabilities
Northern Human Services
One Sky Community Services, Inc.
PathWays of the River Valley
People First of New Hampshire
Self Advocacy Leadership Team

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Christine Santaniello, Associate Commissioner, Department of Health and Human
Services Via Email: Christine.L.Santaniello@dhhs.nh.gov