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March 16, 2022

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Re: Concerns regarding BDS Systems Redesign

Dear Commissioner Shibbinette, Associate Commissioner Santaniello, and Bureau Chief Hunt,

The Quality Council is very concerned about the Department’s plans to redesign the developmental disabilities services system over the next several years. Attached are a summary of our current concerns and questions.

Thank you for your consideration of these questions and concerns. We would appreciate a response in writing to each of these by April 1, 2022.

Sincerely,

Stephanie Patrick, Chair
Carrie Duran, Vice Chair

Quality Council Concerns regarding the Bureau of Developmental Services Redesign

March 16, 2022

Public Information Sessions:

- The webinar format is not accessible to some people including people with developmental disabilities.
- In addition to asking questions via the chat feature, we request that you add an option for participants to ask questions verbally through video.
- Sign language interpretation should be provided for all public information sessions and included on video recordings.
- Answers must be provided in plain language and double speaking should be avoided.
- There is no process for follow up if a participant's question is not fully answered or answered at all.
- We appreciate the meetings with stakeholders, but messaging is not consistent, creating additional confusion. Messaging must be consistent to all groups and stakeholders.
- At times, the answers to questions and concerns during listening sessions are too simple and do not fully address the concern. While plain language is important, this does not mean that you should provide vague or unclear answers to concerns. If you don't know the answer to a question or the topic has not been decided, please say that.
- Despite the fact that BDS has held two listening sessions for families and the general public, we have seen little evidence that BDS is listening to the concerns that families are expressing about this systems redesign or the current waiver process. What can families do to be more effective?

Waiver Development and Redesign:

- We are in the process of implementing a changing rate methodology, direct pay, conflict free case management and IT modernization. We believe that these changes may yield some of the goals of the larger systems redesign. With the workforce crisis and the required changes to the waiver to comply with CMS, we feel like the additional changes are premature and will cause unnecessary stress and upheaval for families who are barely managing now.
- At the information session on March 3, 2022, BDS said that people can be on both the proposed new waivers. We do not believe that the Center for Medicare and Medicaid Services (CMS) allow participation on two 1915(c) waivers at the same time. Please explain.
- Please explain the state's plan to define eligibility for each waiver. What criteria will be used? Will individuals be required to need 24-hour care or residential services for the most comprehensive waiver?
- Will there be budget or enrollment caps on either waiver?
- We are concerned that the two-tiered waiver proposal will limit access to services and create unnecessary delays if an individual must move from one waiver to another. Please explain how the proposed two-tiered system will improve services.
- Habilitation, including the ability of people with disabilities to be engaged in their communities, is a critical part of RSA171A. It is not addressed in the SIS and it doesn't seem to be getting enough attention in the process. Will the new waiver provide services to support habilitation?
- The expectation on families to provide significant free supports to their adult children with disabilities is not realistic. It hurts people with disabilities as they are not allowed the independence that they want and need. It hurts parents who cannot work in the jobs that they love, which can only contribute to NH's workforce shortage. We have not heard any acknowledgement of this reality in these discussions. Will the system redesign address these issues? If not, when will BDS address this issue?
- Please explain how BDS can justify the burden on families to provide unpaid care to their love ones. Is this outlined in state law or regulation? This system cannot continue and we are concerned that this has not been addressed in any significant systems redesign conversations to this point.

- If BDS expects families to continue to provide significant support without compensation, will the state consider changes to state law or policy to support families: property tax relief, interest free loans for modified vehicles, health insurance supplements, etc?
- It seems that PDMS families are being left out of conversations. Why aren't rules consistent across the board? Will the new waiver rules be applied the same if you use PDMS or utilizing area agency services? How would that look different
- Some services are only available in particular regions now. How will BDS assure that all services are available across the state for all people who need them?

Budget and Funding:

- At the information sessions, BDS has said services will not be cut and rates will be improved, but there is no need for additional funding for the system. This does not add up. Please explain in detail how this is possible.
- For years, families have expressed concerns that waiver participants rarely receive increased budgets until a crisis happens. We would like a commitment that BDS will regularly assess the needs of each participant and increase budgets when needs increase.
- Has DHHS made any efforts to educate the legislature on these changes, particularly the likelihood that these changes will increase the cost of developmental disability services?
- At a recent meeting, Chris Santinello said that BDS has legislative support. Please explain this statement. Do you have support from specific legislators or committees?
- According to the A&M report, current individual budgets are not equitable and people are being over served and underserved. We currently use the SIS & PCP to if the plan is to continue using those tools how will the process become more equitable?

Employment:

- We are concerned that the state is not focusing on employment and this will not improve when we move to a two tiered waiver system.
- Current employment services do not meet the needs of people with significant disabilities, with behavior challenges, with communication needs and others. We are concerned that the new waiver system will continue to ignore the employment needs of these individuals.
- Please explain how employment for people with disabilities will improve under the tiered waiver system?