

DISABILITY RIGHTS CENTER - NH

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August 17, 2022

VIA FIRST-CLASS MAIL AND EMAIL

Commissioner Lori Shibinette
NH Department of Health and Human Services
129 Pleasant Street
Concord, NH 03301

Re: Concerns with the Developmental Disability System

Dear Commissioner Shibinette:

In the summer of 2021, the Bureau of Developmental Services (“BDS”) embarked on a “systems redesign” process intended “to update our service delivery system to best support individuals with developmental disabilities and their families throughout their lifespan, today and in the future.”¹ While this goal is laudable, our office has deep concern that the current redesign will fail to address existing gaps in the current developmental service delivery system (“DD System”) that have a damaging impact on individuals with developmental disabilities and their families.

We hope that you will take the opportunity during the redesign process to make meaningful changes to the DD System. This includes addressing barriers to accessing home and community based services and modifying practices in the existing DD System to better meet the needs of people with developmental disabilities, rather than perpetuating the inequities present in the current DD System.

The idea of New Hampshire’s DD System, with care provided regionally by area agencies, was unique and considered a groundbreaking model for other states to emulate in the early 1990s. However, over the last thirty years, deep flaws in this model have emerged on both a statewide and local level. These flaws have become so ingrained that instead of being corrected, they are now considered a necessary, if unfortunate, byproduct of the area agency system. The negative impact that these flaws have on individual service recipients cannot be overstated.

DRC-NH receives calls from dozens of adults with developmental disabilities and their families with concerns about their services each month. Below are a number of critical problems we’ve identified based on our conversations with our clients. The list is by no means exhaustive, but

¹ BDS Systems Work, Retrieved June 2, 2022, <https://www.dhhs.nh.gov/programs-services/disability-care/developmental-services/bds-systems-work>

instead illustrates some of the most concerning problems that DD service recipients routinely encounter and that we have observed in working with our clients.

Concerns About Service Planning and Delivery

Eligibility determinations must be separated from service provision in the redesigned system. Currently, area agencies play a significant role in eligibility determinations for potential DD System clients. However, we see many cases where area agencies spend significant resources litigating our clients' eligibility, even after receiving clear documentation that demonstrates eligibility for services. This adversarial introduction to the DD system makes it difficult for clients and families to trust that the area agency will act in their best interest and provide appropriate services.

Even where eligibility determinations are not adversarial, many participants face significant delays in securing funding for day programming and residential services, delaying services. Delays also affect existing participants seeking to change or amend their individual service agreements.² Some people have waited months or years to receive appropriate services. In one recent example, a DRC-NH client waited for over a year to receive services other than those provided by a family member. During this time, the area agency made little or no effort to address the lack of services, despite regular requests from the individual's guardian.

The person-centered planning process is a right guaranteed to all people in the DD System.³ Yet, we rarely see evidence of person-centered planning in our cases. Area agencies are required to coordinate care "in consultation with the client in the client's place of residence, [and] arrang[e] for and coordinat[e] the delivery of care and services to meet the physical, emotional, medical, nursing, financial, legal and social services needs of the client."⁴ The involvement of people with disabilities and their families in the individual service plan/agreement ("ISP") development process is required because it is critical to ensuring that participants receive appropriate services. However, it does not appear that true person center planning is regularly conducted in the development of the ISP and the ISP does not reflect the preferences and goals of the person with developmental disabilities.

It is common practice for area agencies to provide clients with very few choices and limited flexibility regarding the goals and service options when developing an ISP. Many of the goals and services in the ISPs we review contain the same standardized language and goals, with little variation or personalization. It seems that many ISP goals and services are put in place out of convenience for the area agency, not because many individuals share the same needs. We regularly see participants with relatively complex disabilities with ISPs that are almost identical to clients with less complex needs, even when the proposed supports will not meet their needs. There appears to be no incentive to offer services and supports outside of these boilerplate ISPs

² RSA 171-A requires that BDS and area agencies to allocate funding and provide services within 90 days for newly eligible adults or for participants who have experienced a significant life change. N.H. Rev. Stat. Ann 171-A:1-a.

³ He-M 310.06(a)(4); He-M 503.09(d)

⁴ He-P 819.03

and, moreover, little desire for area agencies to think outside of the box when designing an individual's ISP.

Often, it appears that efforts to find a vendor to provide services are perfunctory at best. Many service coordinators appear content to adopt these boilerplate ISPs and only send requests for proposals ("RFPs") to a small selection of vendors. Some participants and their families have been told that there are no vendors available. Similarly, a common justification for sending out only a few RFPs is that the participant's service coordinator assumes that other potential vendors would not provide services to that individual. Instead of drafting an RFP that will elicit positive responses, some service coordinators are not willing to do more than the bare minimum to help their client find an appropriate service provider.

Lack of permanency planning

Many adults with developmental disabilities want to live independently. However, because New Hampshire's DD System is not designed to provide this level of support, many participants resign themselves to living with their parents, in enhanced family care, or in residential facilities. In many cases such living arrangements are necessary because no other options are offered by the area agency. Discussions about independent living arrangements are often short-lived because the area agency takes the position that their client lacks independent living skills. Yet, concerted efforts to foster these living skills rarely happen and are not included in ISPs. Without proper planning and skills training, adults with developmental disabilities who lack independent living skills, risk unnecessary institutionalization when their parents become unable to provide care and support, a concern we often hear from clients and their aging caretaker parents.

Notices and Appeals

The written notice requirements outlined in the current DD regulations do not reflect federal Medicaid notice requirements. Federal Medicaid regulations require written notice for any "termination, suspension of, or reduction in covered benefits and services".⁵ State regulations give DD participants the right to appeal any "determination, action, or inaction by an area agency".⁶ However, providing written notice of this right is only required in a limited number of circumstances.⁷ We speak with many participants and their families who are not aware of their right to challenge an area agency decision because the regulations do not require area agencies to provide written notice. As a result, many actions that significantly impact a participant's services go unchallenged.⁸ For example, if a participant's budget is reduced, the current regulations do not require an area agency to notify the participant of their right to appeal. The state regulations must be amended to reflect federal Medicaid notice requirements more accurately.

⁵ 42 C.F.R. §201.; *see also* CMS State Medicaid Manual § 2900.1 and §2900.4.

⁶ N.H Admin. R. He-M 517(a).

⁷ Written notice is only required for: (1) adverse eligibility decisions; (2) determinations regarding the choice or removal of a provider; (3) the removal of a service coordinator; and (4) termination of services. N.H. Admin. R He-M 517(c).

⁸ Many participants do not learn about their appeal rights until after the 30-day window to file an appeal has closed.

Accommodations in the Service Delivery Process

People with developmental disabilities and their families in New Hampshire may have a disability that requires specialized services or accommodations to fully meet their needs. For example, participants who are deaf or hard of hearing must have access to qualified direct support and professional staff who communicate in the individual's preferred method of communication. This may require hiring staff who are proficient in American Sign Language, or training staff to use an assistive communication device or other form of individualized communication. Staff who "know a few signs" are not appropriate to provide services to deaf or hard of hearing participants, yet they are frequently hired to do so.

Family inclusion and participation is a cornerstone of the service delivery system for many adults with disabilities. Like participants, some family members may require an accommodation to participate. For example, area agencies will often suggest a participant directed and managed services (PDMS) program as the best way to find staff for clients with complex disabilities. A PDMS program places significant responsibility on the family to manage the program. For family members with disabilities or other challenges, administering a PDMS program may be impossible, leaving their loved one without services and without the support to find the staff they need. Area agencies and service providers must provide needed accommodations to ensure people with disabilities and their family members can fully participate in the developmental services system, even when this requires doing things differently.

Budgetary Concerns

Inappropriate budget reductions are also a common complaint from developmental service participants. Due to the statewide workforce shortage, many people with disabilities and their families struggle to find appropriate services or support staff. If a direct support provider (DSP) cannot be found, a portion of that participant's budget will remain unspent at the end of the year. Many families have reported to us that area agencies reduce that participant's next annual budget because of a lack of services even though the participant's needs have not changed.

When an individual is determined eligible for services, access to appropriate services is not guaranteed. We have spoken with many participants who request additional services or supports but whose case managers refuse to make the formal request to BDS. Sometimes, families are told that if the area agency provides additional supports, it will result in services and funding being removed from another family who needs them more.

Reducing an individual's budget because they cannot obtain critical services or because another family requires additional services is inappropriate. Funding for the DD System is not a zero-sum game. By design, the annual budget for the DD System is supposed to be flexible so that it reflects the actual needs of waiver participants. The developmental services statute mandates that BDS request an amount sufficient to fully fund services for all eligible participants.⁹ BDS and area agencies must find a way to improve communication about anticipated budgetary needs so

⁹ N.H. Rev. Stat. Ann. 171-A:1-a, II.

that all eligible DD clients receive the funding to which they are entitled and that they have access to additional funds as their needs change and as the cost of services increases.

Lack of Available Crisis Services

Crisis services must be available to DD System participants. However, the lack of community-based resources and services devoted to crisis prevention and intervention are so limited that they are often unavailable or unreasonably difficult to access. As a result, many people in crisis are placed in facilities like hospitals or prisons that are not designed or able to meet their needs. In addition, a number of people with developmental disabilities also have mental health needs. These individuals need services from both their area agency and community mental health center. While some progress has been made to coordinate services in some regions, this is not consistent statewide.

The systems redesign must take steps to address the statewide shortage of available crisis services and ensure that all people with developmental disabilities and mental illness receive coordinated services from area agencies and community mental health centers.

Concerns About Participant Directed and Managed Services (PDMS)

We have serious concerns about the overuse of participant directed and managed services across the state. Some families are told that PDMS is the only option to pay competitive wages for the staff that they need, regardless of whether the family has the skills, time, or ability to manage a PDMS program. When they fail, they are blamed for not advertising or recruiting properly. While PDMS is a viable option for some families, it cannot be the only option. Although area agencies necessarily have a more limited role in a PDMS program, agencies should offer assistance to families when needed for the program to succeed.

Because of administrative delays, switching from a traditional to PDMS service model causes significant problems for participants and their families. Although the process to change service models is not complicated, receiving approval from the area agency and BDS can take longer than 6 months.

Finally, many PDMS families report that area agencies take an unreasonably long time to approve direct support professional employees. Even when participants find suitable employees, the area agency vetting process often takes so long that many potential DSPs find a different job as they cannot wait for approval.

The state must devote resources to examining the current PDMS program and addressing identified problems.

Lack of Accountability for Area Agencies

In serving our clients, we regularly meet area agency staff who are committed and trying their best to serve people with disabilities. However, we also encounter staff who are overworked, untrained, and unable or unwilling to do their jobs. There appears to be little recourse to hold

these individuals, or the area agencies who are employing them, accountable. A priority should be decreasing turnover and retaining quality staff. Doing this will allow employees who genuinely want to work as a DSP or case manager to have a viable career path instead of a low paying, short-term job.

The DD System was created to support individuals with developmental disabilities, yet we regularly encounter cases where rules are administered inconsistently. The inconsistent administration of policies and rules often benefits area agencies rather than the clients they serve. It is also very common for area agency staff to provide services based on past practices, which are not always in accordance with current administrative rules and statutory requirements. When we ask area agencies about a questionable practice, a common response is that “this is the way we have always done it.” Unfortunately, area agencies have been unwilling to be proactive and take steps to ensure that staff provide services pursuant to the relevant rules and regulations. Flexibility in the administration of DD services is only helpful if its implementation helps to better meet the individual needs of the service participant, not the area agency.

Concerns Regarding the ITS System

The Intensive Treatment Service Program (ITS) is intended to serve individuals with histories of high-risk behaviors, providing a combination of intensive treatment, enhanced supervision, and environmental modifications. We understand that some people with developmental disabilities need this high level of support, but we have serious concerns about the current program. We see significant delays in completing required risk management plans and related evaluations, and no opportunity for the participant or their guardians to provide input into the beneficial programs or type of care they receive. These delays often cause the individual to remain in hospitals or other institutional settings far longer than is necessary.

The information considered and relied upon by the ITS committee in making recommendations often does not paint a complete picture of the individual. Risk management plans, related evaluations, and RFPs often contain inaccurate, outdated, and misleading information and there is no process to correct this information. If the information in the RFP is inaccurate, then provider responses are more limited and proposed services and settings are unnecessarily restrictive.

The level of secrecy in the ITS process is concerning. We recognize that the sensitive nature of a client’s history and discussions about the level of appropriate services requires some measure of confidentiality. However, the current ITS process operates on a level of almost complete secrecy. There is no opportunity for clients, their families, or advocates to provide more information before recommendations are made. This lack of access means that individuals are not afforded an opportunity to provide information that would help the committee make more informed decisions. As a result, it is impossible to know if the decision-making process was fair or whether the recommendations were predetermined.

This letter outlines some of DRC-NH’s concerns with the current DD System and its impact on individuals with disabilities and their families. The DD System must function effectively and efficiently to secure the least restrictive services for participants in their home community. The state must take advantage of this redesign opportunity to transform the DD System to truly meet the needs of people with developmental disabilities. DRC-NH encourages the State to discuss the

concerns raised in this letter, as well as those raised by other community members, as part of the redesign process.

Thank you for your commitment to people with disabilities and to addressing these concerns. We look forward to continuing to work with you on these issues during this redesign.

Sincerely,

A handwritten signature in black ink that reads "Stephanie Patrick". The signature is written in a cursive, flowing style.

Stephanie Patrick

A handwritten signature in black ink that reads "Pamela Phelan". The signature is written in a cursive, flowing style.

Pamela E. Phelan

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