DISABILITY RIGHTS NEW YORK

New York's Protection & Advocacy System and Client Assistance Program

March 19, 2018

Office for People Developmental Disabilities
Attn: Division of Person Centered Supports
Fifth Floor
44 Holland Avenue
Albany, New York 12229
peoplefirstwaiver@opwdd.ny.gov

Re: Comments on Amendment 03

To Whom It May Concern:

We write to express our concerns regarding the Department of Health ("DOH") and the Office for People with Developmental Disabilities ("OPWDD") proposal: *Amendment 03* ("Plan"). As the statewide Protection and Advocacy system for people with disabilities, Disability Rights New York ("DRNY") has an interest in ensuring that people with disabilities receive the support they need to live independently in their communities. We appreciate DOH and OPWDD's commitment to these goals. However, DRNY is not convinced that care coordination organizations ("CCO") and a managed care system is an appropriate and effective delivery system for people with intellectual and developmental disabilities. We offer the following comments on the proposed Plan to make it more conducive to serving this community.

I. Plan Development

The Plan is Inaccessible to Most OPWDD Service Recipients and Violates the ADA

Under Title II of the Americans with Disabilities Act, OPWDD is required to take steps to ensure its communications with people with disabilities are as effective as communications with people

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who do not have disabilities.[1] However, the over five hundred page technical Plan is neither clear nor effective communication for people with intellectual and developmental disabilities. The length, coupled with the format makes the Plan inaccessible. The absence of an introductory overview, table of contents and index renders it difficult for attorneys, let alone lay people, to comprehend. These omissions, coupled with the failure to provide the Plan in plain language, renders the Plan inaccessible to the people it will impact most.

Moreover, the Plan, as well as the entire transition process to care coordination and managed care, is so unwieldy and unclear, that many people with intellectual and developmental disabilities and their families are unaware of the magnitude of changes to come, and unable to meaningfully understand the Plan. It is difficult to find any language in the Plan granting the right to receive the document in plain language, and Medicaid Service Coordinators ("MSC") have not yet introduced the changes to their clients in meetings, giving them no opportunity to review and possibly comment on the Plan. Instead, the people most directly impacted by the proposal are left to rely on information from their MSCs, and only after the time period for comments has expired.

Ineffective Solicitation of Stakeholder Comments

Even those stakeholders who are able to comprehend the magnitude and complexity of the Plan may not have a meaningful opportunity to comment due to the ineffective publicizing of this notice and short comment period. The public notice was posted to the New York State Register and open for public comment for a 30-day period, the minimum amount of time permissible under N.Y. A.P.A. Law § 202. Aside from the Register, however, the opportunity for public comment was poorly publicized to stakeholders, especially service recipients and their families. It is not easy to find out about the Plan and comment period from either OPWDD or DOH's websites; both agencies could have easily included this information on their respective websites. For example, OPWDD has specific web pages dedicated to managed care, yet no information about the Plan or comment period is included. While the text of the Plan can be found on OPWDD's website, that link contains no information about the process or period for public comment. There is no credible reason OPWDD's web page titled "Outline of Outreach Activities Related to OPWDD Transition" fails to notify the public of the Plan and comment period. All previous notice and comment periods are posted there. While this would be a logical, expected, and accessible place to publicize the current opportunity for comment, the last update is dated January 24, 2018; it does not include either the posting of the Plan or the comment period.

Further, OPWDD and DOH were not forthcoming that an amended Plan would be issued for public comment. Consequently, it is quite possible for the Plan to have been missed entirely by individuals who were not monitoring the New York State Register on February 14, 2018. This is particularly concerning, though not surprising, given that the previous Plan and comment period took place over the December holidays, a difficult time at best to seek meaningful public comment.

[1] 28 C.F.R. §35.160 (2005).

With the scheduled sunset of the current waiver rapidly approaching, this is one of the last opportunities to express concerns and provide input. DOH and OPWDD have effectively precluded meaningful stakeholder input.

The Plan is Inaccessible to Persons with Limited English Proficiency and Violates the State's Language Access Plan

OPWDD and the DOH did not make the Plan readily available in languages other than English. OPWDD's failure to translate the Plan into the six languages identified in its Language Access Plan ("LAP") hinders meaningful stakeholder involvement by non-English speakers and violates the New York State and OPWDDLAP.

With two and a half million New Yorkers who have Limited English Proficiency ("LEP"), New York has implemented a statewide LAP. The LAP requires executive agencies that provide "direct public services" to translate "vital documents" including essential documents relevant to services offered[2] The LAP requires such documents to be translated into the "six most common non-English languages spoken by individuals" who identify as LEP.[3] Unquestionably, the Plan impacts services for persons with intellectual and developmental disabilities who are LEP. Therefore, the Plan should have been made publicly available in the six languages identified by OPWDD's LAP.

DRNY has also received complaints regarding the Plan's translation when it was requested by stakeholders. OPWDD provided these stakeholders with documents other than the Plan. Furthermore, when the actual Plan was translated by OPWDD, it was done so in a manner that was confusing and incomprehensible. Therefore, the Plan is inaccessible to those who identify as LEP and want to comment during an already tight comment period. This inexcusably excludes a significant number of stakeholders and their families from the comment process.

II. Comments on the Plan

Given that the 300-page plan is largely incomprehensible, DRNY limited its comments to those issues where we have received complaints.

Care Coordination Organization Selection & Impact on Rural Communities

DRNY received complaints regarding OPWDD and DOH's selection process for its six designated Care Coordination Organizations ("CCO"). The designation process lacked transparency and will likely exacerbate existing barriers to accessing services in rural communities.

DOH and OPWDD received ten letters of interest from entities intent on forming a CCO. However, the DOH posted only six of the letters on its website, months before designating the same six entities as the CCOs. For the sake of transparency, all letters of interest should have been publicly disclosed.

[2] *See* State of New York, Executive Order 26 "Statewide Language Access Policy" (2011).
[3] Id.

In addition, several of the designated CCOs' administrators or boards are composed of former high-ranking OPWDD officials. For example, Care Design NY LLC's executive director, James Moran, recently retired as OPWDD's Acting Executive Deputy Commissioner. DRNY is advised that the five other CCOs likewise include former OPWDD officials as administrators or board members. We cannot confirm this allegation due to a lack of public information about the identity of key officials in the CCOs. Without transparency, the CCO designations are highly suspect.

Moreover, it is impossible to discern the criteria used by OPWDD and DOH in selecting the CCO designees and denying the other applicants. Significantly, the rejected applicants are the most knowledgeable and experienced in providing coordinated care in the state's most rural communities. Indeed, OPWDD and DOH's designation of the six CCOs could have a profound negative impact on individuals with intellectual and developmental disabilities in rural communities. Supports and services for these individuals are already difficult to coordinate and obtain. In fact, OPWDD and DOH's selection of the six CCOs offers fewer options for case management services in rural communities. According to DOH's emerging CCO regional coverage map, in six rural counties in the northern part of the State, there is only a single option for care coordination.

It is also problematic that none of the six designated CCOs appear to have any base of operation in the rural communities they are required to serve. Instead, some of the CCOs will provide only remote care coordination. This is problematic for a variety of reasons. Individuals and their families will have no direct access to their CCO. The care coordinators will have little knowledge of the communities and local services and resources they are required to serve. For instance, a CCO in Albany would likely struggle to connect an individual in Franklin County to volunteer opportunities or know what services existed in the event a family was in need of emergency assistance because of an eviction or foreclosure.

The future implementation of managed care organizations ("MCO") in rural communities could also provide greater challenges than in other parts of the State. Individuals in rural communities are already twelve percent less likely to receive any Home and Community Based Waiver Services than their urban counterparts; they are also twelve percent more likely to use services in a nursing home.[4] Given the cost of travel and the scarcity of direct service professionals, MCOs and CCOs will face the same challenges. The Plan does not appear to make any specific provisions to address this persistent problem. Remote operation will likely exacerbate this problem.

When individuals are enrolled in managed care, they will be forced to obtain long-term supports and services ("LTSS") and health services from providers in their MCO's network. "Economies of scale make it more difficult for rural providers to dedicate resources to integrating care across the health and LTSS deliver systems."[5] Furthermore, rural communities already have significant health service gaps with severe shortages in physicians and specialists which requires residents to

[4] Andrew Coburn and Jennifer Lundblad, Rural Long-Term Services and Supports: A Primer, 6 (November, 2017), accessible at: http://www.rupri.org/wp-content/uploads/LTSS-RUPRI-Health-Panel-2017.pdf

[5] Eileen Griffin and Andrew Coburn, Integrated Care Management in Rural Communities, 11 (May, 2014), accessible at: https://muskie.usm.maine.edu/Publications/rural/Integrated-Care-Rural-WorkingPaper.pdf

utilize tertiary medical providers.[6] These difficulties make it challenging for an MCO to construct a provider network in rural areas, as MCOs "can threaten rural health delivery systems with selective contracting that omits local providers."[7] Accordingly, Vermont required MCOs to contract with any willing medical provider who could meet the plan's contract terms ensuring access to medical services in rural communities.[8] However, it is unclear if New York has included similar language in its contract with MCOs, as a sample contract has not yet been released to the public.

As DRNY has previously commented, when managed care was implemented in Wisconsin, it was first piloted it in a rural setting and the State studied its impact there. Despite this more cautious approach, significant challenges arose after managed care was implemented in Wisconsin. Three MCOs became bankrupt and three others were forced to consolidate due to financial issues. Notwithstanding these lessons, New York is rushing implementation without the necessary assessments on how care coordination and managed care might impact rural communities. OPWDD and the DOH should conduct a study on the possible impacts that the designation of the six CCOs and managed care might have on rural communities before implementing it there.

III. Conclusion

The DOH and OPWDD's Plan is inaccessible to most readers including individuals with intellectual and developmental disabilities. Although OPWDD and DOH have provided a small number of regional forums to reach stakeholders, those efforts fail to meaningfully inform critical stakeholders of the specific procedures and impact the shift to CCOs and managed care will have. Rather than providing a transparent, open process, OPWDD and DOH's minimal efforts to provide notice and opportunity for stakeholder involvement and feedback. Further compounding this inadequate outreach effort is OPWDD and DOH's lack of readily available and linguistically competent translation of the Plan, making it impossible for people with LEP to effectively comment.

While the Plan is couched in language of improving access to services, there is still much too little information to meaningfully assess the State's plan. The consolidation of case management into the six CCOs offers individuals with intellectual and developmental disabilities little choice in case management, rendering them even more vulnerable to service deficits. Before implementing the Plan, OPWDD and DOH must conduct further outreach to stakeholders, and provide clarification and transparency in the CCO designation process and allow for the creation of additional CCOs. Finally, DOH and OPWDD must conduct a study on the impact that CCOs and managed care might have on services for people with intellectual and developmental disabilities in rural communities in order to ensure that there will be no significant disruption in services before they implement the Plan. DRNY would welcome the opportunity to participate in this process.

[6] Id., at 12.
[7] Id.
[8] 8 V.S.A. § 4089b (2015).

Sincerely,

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