DISABILITY RIGHTS NEW YORK

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

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Acting Commissioner
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Re: Draft ID/DD 1115 Waiver

Dear Mr. Helgerson and Ms. Delaney:

We write to express our concerns regarding the Department of Health's ("DOH") and the Office for People with Developmental Disabilities' ("OPWDD") proposal: *Draft ID/DD 115 Waiver* (hereinafter referred to as "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 the DOH's and OPWDD's commitment to these goals. While DRNY is far from convinced a managed care system is an appropriate and effective delivery system for people with ID/DD, we offer the following comments on the proposed Plan.

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I. Plan Development

Lack of Stakeholder Participation

The DOH states that its Plan is an outgrowth of specific recommendations made by OPWDD's Transformation Panel. However, aside from recommendations made by Mr. Helgerson it does not appear that the move to managed care was something specifically recommended by other participants in the Transformation Panel. Rather as stated in the Plan itself, the impetus for moving to managed care is Governor Cuomo's desire to "conduct a fundamental restructuring of (the) Medicaid program to achieve measurable improvement in health outcomes, sustainable cost control, and more efficient administrative structure."

Furthermore, of the 18 members of the Transformation Panel, only two are parents of individuals with disabilities and only one is a self-advocate; direct stakeholder representation by recipients of OPWDD is shockingly inadequate. Similarly, representatives of self-advocacy and disability rights organizations, as well as any other organizations or agencies that represent the interests of people with disabilities, must be involved in this process. Excluding these voices compromises effective transition and implementation of managed care.

Meager Stakeholder Outreach

The Plan for Individuals with ID/DD does not detail outreach efforts by the DOH and OPWDD to engage stakeholders regarding the eventual discontinuance of fee for service ("FFS) Home and Community Based Services ("HCBS") and the mandated enrollment into managed care by 2022. To date, New York State's outreach efforts regarding managed care have been insufficient. For instance, DRNY only learned of the open comment period for OPWDD and DOH's plan through a google alert. DRNY actively monitors public policy developments affecting New Yorkers with disabilities. If we were unaware of the opportunity to comment on these highly relevant proposed changes to eventually mandate managed care for people with intellectual and/or developmental disabilities, it suggests the State's outreach efforts are grossly ineffective, particularly to people with disabilities and other key stakeholders. Moreover, aside from one OPWDD webinar offered on August 7, 2017, OPWDD has conducted no other outreach efforts to individuals with intellectual and/or developmental disabilities or their families regarding the significant changes that OPWDD and the DOH are proposing. For many individuals with intellectual and/or developmental disabilities and their families this webinar was inaccessible for those people that lack a computer and the internet.

Not surprisingly, the Plan lacks any meaningful information regarding outreach to service recipients and families regarding the move to managed care. Instead the Plan states "OPWDD will outline further strategies utilized in reaching out to all stakeholders, including individuals and families, providers, etc . . ." This is woefully inadequate. The DOH and OPWDD should provide specificity regarding the outreach efforts it intends to make in its Plan before submitting it to the Centers for Medicare and Medicaid ("CMS").

The Plan is Inaccessible to Most Stakeholders

The Plan's organization, formatting, and language make it nearly impossible to understand and assess its significance unless someone has a graduate degree in public policy, administration, or health. This is particularly concerning because it may prevent people with disabilities and other key stakeholders from being able to provide any meaningful feedback. While OPWDD provided a summary of its Plan, this document is not written in plain language and fails to summarize all the key concepts, points, and steps discussed in the actual Plan.

The Plan relies heavily on acronyms for terms or entities that the average reader may not be familiar with. There are sometimes as many as four different acronyms in a single sentence. This may render it confusing to stakeholders who do not have a background in public policy or struggle with complex language. Where possible, agencies should replace the acronyms in their plans with shorthand words or phrases that more clearly reference what they refer to.

The Comment Period was Inadequate

While the Plan states that public notice was provided by the DOH submitting the Plan to the State Register on July 14, 2017, it was not until July 25, 2017 that OPWDD announced on its website that it was seeking comments regarding the Plan. The vast majority of stakeholders have no idea how to access the Register. If stakeholders learned of the Plan from OPWDD's website, most had less than 30 days to review and respond to the Plan during prime vacation season. All these factors suggest an intent to prevent stakeholder feedback and involvement.

II. Comments on the Plan

Lack of Due Process Protections

The Plan lacks any due process protections or procedures for individuals in the proposed managed care system. Moreover, it is entirely unclear if a managed care organization ("MCO") will be able to terminate, suspend, or discontinue services. If so, what is the procedure to challenge the decision. Presently, 14 NYCRR 633.12 provides individuals with due process protections and allows individuals to initiate an objection "related to facilities or HCBS waiver services . . . regarding: (i) any plan of services . . . . (ii) plans of placement . . . . (iii) proposal initiated by the agency/facility to discharge . . . . (iv) a proposal to reduce, suspend or discontinue HCBS waiver service(s).

The Plan fails to discuss the process for appealing an adverse decision, initiating an objection, or requesting a Medicaid Fair Hearing. The DOH and OPWDD must incorporate and prescribe specific due process protections under managed care.

Planning and Testing Period is Woefully Inadequate

The DOH and OPWDD state that they will assess the viability of managed care during the voluntary enrollment period. This plan is therefore akin to building a plane while you are

currently in the process of flying it. When managed care was implemented in Wisconsin, the State first piloted it in urban and rural settings, then assessed what it had learned before implementing it statewide. Despite this more cautious approach, significant challenges arose after managed care was implemented in Wisconsin, with three MCOs becoming bankrupt and three others forced to consolidate due to financial issues.

Despite these lessons, New York is rushing implementation without the necessary assessment of whether this is a viable model for our large and complex State. OPWDD's managed care pilot known as Developmental Disabilities Individual Support and Care Coordination Organizations ("DISCOs") have to date been unable to demonstrate that they are a viable alternative to FFS. Moreover, OPWDD has failed to fully assess DISCOs and provide any report on their viability.

The DOH and OPWDD must conduct a study of its DISCOs and identify barriers and test modifications within these pilots before it seeks to implement mandated enrollment in managed care statewide. In addition, OPWDD and the DOH should pilot managed care in a rural area of the state so that it can assess any additional barriers in this type of location.

Capitated Pools will Significantly Impact Services for Individuals with Complex Needs

The Plan states that 24 months after the implementation of mandated managed care in 2022, individuals with complex needs who are in need of specialized services will be placed in risk-based capitated payment pools with MCOs. Accordingly, individuals with intellectual and/or developmental disabilities who have complex and intense needs medical or behavioral needs will be given the same funding levels as other individuals who have significantly less needs. This plan is therefore unworkable.

Even under the current system, individuals with the most complex needs lack services they are approved to receive. For example, dozens of individuals at the remaining Developmental Centers are eligible for discharge with enhanced funding, but remain institutionalized. Similarly, over 200 adult graduates at residential schools are languishing in institutional settings despite enhanced funding. Consequently, if OPWDD and the DOH eliminate enhanced funding for these and other individuals with complex needs, DRNY anticipates that the number of people unable to access community based services will only grow, as will the number requiring institutionalization. Accordingly, if the DOH and OPWDD do implement managed care it must continue to provide enhanced funding for these individuals above and beyond the capitated rate so the new development and services can be implemented for individuals with the most complex needs.

The Plan Lacks Needed Specificity Regarding Enrollment in MCOs

The Plan is silent as to whether an MCO must enroll every individual who seeks to participate in its plan. If an MCO has the discretion to cherry pick its enrollees, people with complex behavioral and medical will suffer, particularly under a capitated model as there would be an incentive for MCOs to only enroll people who require less services. If this were to occur it is likely that individuals with complex behavioral and medical needs would be unable to find an

MCO.

In fact, when managed care was implemented in New York City for elders, MCOs signed up "vigorous older adults . . . whose health needs [were] relatively small [and] deterred people who were bedbound or affected by dementia from enrolling in a plan . . . or by falsely saying that the plan's budget or policies did not allow as much care as the person needed."[1] Accordingly, federal law requires MCOs to "prohibit discrimination on the basis of health status or requirements for health services in enrollment, disenrollment, and reenrollment." 42 U.S.C. § 1396b(m)(2)(A)(V). Therefore, the DOH must mandate that an MCO enroll any eligible individual who seeks its services and an MCO cannot dissuade someone from enrolling.

Unclear who will Determine Eligibility for Managed Care

It is unclear from the Plan that once enrollment in managed care is mandated, if eligibility for services will continue to be determined by OPWDD's Developmental Disabilities Regional Offices ("DDRO") or by the MCOs themselves. The DOH and OPWDD should provide clarification regarding this issue. If the MCO's will be determining eligibility for services it is concerning that a non-state entity will be interpreting New York State's Mental Hygiene Law.

Furthermore, the Plan does not discuss the appeals process if someone is denied eligibility for managed care and how someone can request a Medicaid Fair Hearing and under what circumstances. The DOH and OPWDD must provide specificity regarding whom will determining eligibility for managed care and potential appeals of adverse eligibility decisions.

Eligibility for Managed Care is too Restrictive

While the Plan references New York State Mental Hygiene Law § 1.03(22) regarding eligibility for community based services through an MCO, it is silent as to how the law will be interpreted. Currently OPWDD, utilizes memoranda in interpreting eligibility for its services which contain alleged rules that have severely curtailed eligibility for individuals with intellectual and/or developmental disabilities who had been previously served by OPWDD including people with Asperger syndrome, pervasive developmental disorder NOS, traumatic brain injury, learning disability, and attention deficit hyperactivity disorder, as well as individuals with co-occurring psychiatric disorders. Moreover, OPWDD has re-defined the definition of a developmental disability pursuant to Mental Hygiene Law § 1.03(22)(a)(2) so that it now only applies to people with muscular dystrophy.

However, the plain meaning of the statute has a broader definition and states that a developmental disability is: "attributable to any other condition of a person found to be closely related to [ID] because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that [of a person with ID] **or requires treatment and services similar to those required for such person**." Mental Hygiene Law § 1.03(22)(a)(2) (emphasis added). Because the Plan fails to articulate the parameters of eligibility, it is impossible to assess the impact on

[1] New York Times, Advocates Say Managed-Care Plans Shun the Most Disabled Medicaid Users, (April 30, 2013), accessible at: http://www.nytimes.com/2013/05/01/nyregion/advocates-say-ny-managed-care-plans-shun-the-most-disabled-seniors.html

individual with intellectual and developmental disabilities. OPWDD and the DOH must clarify eligibility.

Furthermore, the Plan provides a new rule that further restricts eligibility. The Plan states that "[o]nset of significant limitations in adaptive behavior constituting substantial handicap, must be before the person attains age 22 in order to satisfy the requirements of NYS Mental Hygiene Law 1.03(22)(b). Onset must be verified as detailing the occurrence of significant limitations in adaptive behavior prior to age 22." This rule would make it impossible for individuals to obtain eligibility for services whom are over the age of 22 and do not have an adaptive behavior assessment which was conducted prior to turning 22 demonstrating that they had a substantial handicap. Consequently, these individuals would be unable to obtain services. DRNY has seen numerous examples of individuals in their 50s and 60s seeking eligibility due to the decline or death of their family caregivers. Many times, their childhood records are simply unavailable. Moreover, the documentation requirement is not found in the Mental Hygiene Law which stipulates the OPWDD eligibility requirements. DRNY strongly recommends that the DOH and OPWDD not implement this rule.

Lack of Skilled Nursing Services will Decimate Care at Home Waiver

The consolidation of OPWDD's Care at Home ("CAH") Waivers into managed care is highly problematic. The CAH Waivers are designed to allow medical fragile children to remain at home with their families as opposed to placement pediatric nursing facilities. Accordingly, many of these children are in need of skilled nursing services at home so that they can remain in the community. However according to the Plan, skilled nursing will no longer be a service that a medically fragile child will be eligible to receive through managed care. The DOH and OPWDD must amend its Plan so that skilled nursing is included to avoid unnecessary institutionalization.

Structure of MCOs May Create Conflict of Interest at the Expense of Individual Needs

It is entirely unclear from the Plan what the structure of MCOs will be and whether they will be required to be not-for-profit entities. If it is possible that an MCO could be a for-profit entity under a capitated payment arrangement, MCOs are incentivized to exclude individuals with complex needs or limit the amount of services an individual can participate in. Therefore, the DOH and OPWDD should mandate that MCOs are one hundred percent not-for-profit entities.

In addition, it is concerning the DOH and OPWDD are proposing that a Health Home agency that provides case management for someone could apply to become an MCO. If this were to occur, there could be the potential for a conflict of interest in providing individual services enrolled in the Health Home as there would be an incentive under a capitated payment model to have individuals underutilize services. Consequently, the DOH and OPWDD should not allow Health Homes to become MCOs.

Lack of Specificity Regarding the Designation of MCOs

The Plan states that agencies that have a demonstrated ability to deliver HCBS services will be permitted to apply to become an MCO. However, it is entirely unclear how OPWDD and the DOH will make these determinations. Furthermore, the Plan lacks a sample contract that it will be using with MCOs. Instead the Plan states that this will be outlined in a further document.

OPWDD and the DOH must provide a sample contract for MCOs in its Plan and provide clarity and specificity regarding how an agency can demonstrate it has the ability to deliver HCBS services.

Shortage of Services and Workers is Not Addressed:

The Plan fails to address how an MCO will ensure the delivery of HCBS services to individuals. DRNY has received numerous complaints that individuals who are eligible for HCBS services are unable to actually obtain these services due to a dearth of direct support professionals ("DSP") and low wages for these workers. Consequently, individuals with complex needs are forced to receive services in institutional settings including hospital emergency rooms, nursing homes, intermediate care facilities, and psychiatric centers.

The Plan fails to identify how MCOs will be able to rectify these issues. According to NYSARC "80 % of agencies surveyed indicate that DSP staff turnover and retention is already a serious problem [with] turnover . . . already close to 20% a year."[2] In addition, the shortage of DSPs results "in an inordinate dependence on overtime with survey respondents reporting more than 2.9 million hours in one year."[3] Given these significant gaps in the DSP workforce, the DOH and OPWDD must provide detailed recommendations as to how it intends to fund and ensure the adequacy of HCBS services given the ongoing failure of the service delivery system to meet confirmed needs. OPWDD and DOH must formally and thoroughly assess the gaps in the service delivery system and ensure a managed care model does not continue or exacerbate this issue that so often results in unnecessary and illegal institutionalization.

The Plan Does Not Ensure Service Recipients Have a Choice of MCO Provider

If managed care is mandated in New York State, it is unclear if individuals will have any meaningful choice between MCOs. The Plan lacks any specificity or clarity of how many MCOs will be operating in each OPWDD region. Consequently, it is possible that an individual might be limited to choosing one MCO. The Plan must mandate that each region have at least more than one MCO in operation so that individuals with intellectual and/or developmental disabilities receive appropriate services from agencies that have an interest in performing well.

Services may be Inadequate if Recipients are Limited to In-Network Services

If managed care is mandated in New York State, individuals will only be eligible to receive services from agencies and providers that are in the network of their MCO. This would fundamentally limit the individual's choice of providers at the discretion of the MCO. DRNY has already received a complaint regarding concerns about the ability to access necessary in-network services from the MCO Partners Health Plan ("PHP"). It is DRNY's understanding that an individual with a developmental disability is unable to be discharged from a hospital to the community because this person is unable to obtain physical therapy from PHP's network. In

[2] NYSARC, Supporting People with Developmental Disabilities: The Impact of Low Wages and the Minimum Wage Debate on the Direct Support Professionals Workforce, 3, (2015), accessible at: https://www.nysarc.org/index.php/download_file/view_inline/331/
[3] Id, at 2.

addition, this individual is unable to obtain the number of home health aide hours a week from PHP. Accordingly, the DOH and OPWDD must allow for a waiver so that individuals who are unable to obtain necessary services from in-network providers of the MCO to obtain these supports outside of the network.

MCOs and Title III of the Americans with Disabilities Act:

The MCO Partners Health Plus (PHP) lists which of its in-network clinical, behavioral, and medical services are able to comply with the all elements of Title III of the Americans with Disabilities Act ("ADA"). According to this information, the vast majority of PHP's in-network providers are unable to be fully compliant with Title III of the ADA. It is troubling that an MCO which manages services for people with intellectual and/or developmental disabilities would have providers in-network that are unable to comply with the ADA. The DOH and OPWDD must mandate that all provides in MCOs comply with the ADA as they are already legally required to do under federal law.

Failure to Address Transitional Care Planning for Students

The Plan is entirely silent as to whether individuals in residential schools who have completed their education and are ready for discharge to the community will be enrolled in managed care. Currently, there are over two hundred young adults who have graduated from in-state and out-of-state residential schools who remain in these institutional settings because OPWDD has not provided timely and sufficient discharge planning. Many of these individuals have been waiting years for a discharge plan that would allow them to return to the community.

Currently, OPWDD provides transitional funding for these individuals until a discharge plan can be developed. In addition, OPWDD provides enhanced funding for these individuals to entice an agency to serve them in the community. The Plan fails to specify how transitional and enhanced funding will operate. Likewise, there is no provision for discharge planning and care coordination for such individuals.

No Specificity Regarding Individuals who Opt Out of Health Homes:

The Plan states that individuals who choose to opt out of Health Homes for case management when managed care is implemented will receive case management from a State designated entity. It is entirely unclear what this entity will be, the selection process for choosing this entity, and the fee structure. The DOH and OPWDD must provide specificity regarding this State designated entity.

Failure to Specify MCO Rate Calculation:

The Plan lacks any details regarding how capitated rates will be set for MCOs other than to say that they will be "consistent with actuarial soundness requirements at 42 CFR 438.6(c). [] No variation is expected." It is disconcerting that the Plan lacks any details regarding the rates and how they will be set. If the FFS rates are to be used as a basis for capitated rates, this would be ill-advised as these rates are already so low that it is difficult to attract direct support

professionals to deliver the services. The DOH and OPWDD should set the rates in the Plan itself after conducting an assessment regarding barriers with the current FFS rates.

Lack of Clarity Regarding the Role of the DDRO and DDSOs under Managed Care:

It is entirely unclear from the Plan what the future role of OPWDD's DDROs and the Developmental Disabilities Services Offices ("DDSO") will be if managed care is mandated. For example, the DDRO hosts the Residential Opportunities Committee which facilitates the placement of individuals who are in crisis, homeless, or being abused and neglected. Under the Plan, it appears that this would become the function of the MCO. Similarly, MCOs would presumably be responsible for assisting individuals in crisis who are in need of community based services in their homes, a function currently placed with the DDRO. However, the Plan fails to plainly place responsibility for these essential functions for individuals in crisis.

While silent on the issue, it would appear that under the Plan the DDSO would cease to exist as an entity unless OPWDD would be contracting with MCOs to provide services to individuals in State operated settings. This is concerning not only because it would effectively mean the privatization of thousands of State employees who are DSPs, but also because historically the DDSO was always the provider agency of last resort for people with complex needs.

When individuals with complex behavioral needs, medical needs, forensic backgrounds, and those individuals who display inappropriate sexual behaviors are unable to receive services from non-profit agencies, the DDSO oftentimes provides these individuals with care and treatment. If the DDSO were to cease to exist, it could potentially be impossible for these individuals to obtain services from an MCO.

If OPWDD and the DOH intend on eliminating the DDSO and truncating the DDRO, it should state so in its Plan. If so, the Plan should provide additional specificity on how MCOs will provide services to complex, hard-to-serve individuals and those in immediate need.

Lack of Clarify Regarding the Future of State-Funded Services

Presently, OPWDD provides State-funded services for individuals who do not live in eligible HCBS settings such as children in residential schools. State-funded services allow such children to receive respite and community habilitation when they are in the community with their families during school breaks and holidays. It is unclear from the Plan if State paid services will continue. The plan should clarify how these essential services will be funded.

There is No Provision for Family Supports and Services

The Plan does not address whether individuals and their families will be able to continue to receive Family Supports and Services ("FSS") funding. FSS funds are a critical service for individuals living at home with their families that provide funds for: respite, after school programs, sibling support groups, family counseling, reimbursement for goods and services, transportation, and emergency supports in the face of eviction or loss of utilities. The Plan should state whether FSS funding will continue under managed care and if so how funding will be obtained and approved.

Lack of Specificity Regarding Ombudsman Program:

While the Plan states that New York State will contract with an entity to operate the managed care ombudsman program, it is entirely unclear what this entity will be, the selection process for choosing this entity, and the fee structure. The DOH and OPWDD must provide specificity regarding the managed care ombudsman.

The Plan Lacks Operating and Admission Procedures for Developmental Centers

The Plan states that individuals living in Developmental Centers (DCs) will later be phased into managed care. The Plan fails to specify who will be operating the DCs as well as admission criteria and procedures. Presently OPWDD's Bureau of Intensive Treatment and Services determines if someone should be placed at a DC and the individual is provided with due process protections and representation from Mental Hygiene Legal Services. OPWDD and DOH must provide specificity and clarity regarding the proposal to later incorporate the DCs into managed care and what this would look like.

Failure to Address Enrollment of Individuals in Intermediate Care Facilities and Children's Residential Projects

The Plan states that individuals living in community based intermediate care facilities (ICFs) will be enrolled in managed care. However, OPWDD has previously stated that by October 1, 2018, all ICFs will be transitioned to individualized residential alternatives ("IRAs"), and the only remaining ICFs in New York State aside from those at the DCs, will be at Children's Residential Projects ("CRP"). It is unclear from the Plan if this means that OPWDD will no longer be transitioning its community ICFs to IRAs. The DOH and OPWDD should provide clarity on this issue.

In addition, the Plan as written is silent as to whether a CRP, as a jointly funded program between New York State Education Department and OPWDD, will be incorporated into managed care. The DOH and OPWDD should provide clarity on this issue as CRPs serve a critical need for students with disabilities.

III. Conclusion

The DOH and OPWDD's Plan is not based upon any input from people with intellectual and/or developmental disabilities, but instead appears to be a proposal by Governor Cuomo to potentially contain Medicaid costs. OPWDD and the DOH have not conducted an assessment to determine if managed care is a viable option for New York State's intellectually and developmentally disabled population. Indeed, the managed care pilots that have been trialed thus far have been unsuccessful. Given this background, it is unclear how OPWDD and the DOH intend to make managed care work when it is mandated by 2022.

Managed care could potentially be a viable alternative in the future, but to date the DOH and OPWDD have failed to take the necessary steps to assess whether it could work in New York State. The Plan itself lacks clarity and guidance on a variety of issues. Instead of laying the necessary groundwork for managed care, it is troubling that OPWDD and the DOH intend on rushing to implement a system in New York State whose viability is entirely unproven and could thus have disastrous consequences.

In fact, when managed care was implemented in Kansas, it was disastrous for people with intellectual and developmental disabilities. According to Disability Rights Kansas, when managed care was implemented there, "it became a constant battle [with managed care companies for individuals with disabilities] to get what you're entitled to . . ."[4] Services were cut substantially at the sole discretion of managed care companies.[5]

While DOH's Plan is couched in language of improving access to services, it appears quite unlikely MCOs will actually be able to do this given the significant discretion entrusted to the agencies, conflicts of interest, and existing systemic barriers in the OPWDD service delivery system. In addition, under a capitated payment model, MCOs would have an incentive for people to underutilize services. Ultimately, this would likely result in lack of access to community based services and institutionalization for individuals with complex needs. Last, but certainly not least, the Plan lacks any procedural due process protections for individuals regarding their Medicaid funded services.

As written, the DOH and OPWDD should not implement this Plan, as it will have far reaching negative effects on individuals with intellectual and developmental disabilities regarding their community based services. The DOH must conduct further outreach to stakeholder, clarification, measurable outcomes, and development of its proposal. DRNY would welcome the opportunity to participate in this process.

Sincerely,

Julie Michaels Keegan

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[4] Kansas Health Institute, KanCare Not Working for People with Disabilities Advocates Say, (July, 7, 2015), accessible at: http://www.khi.org/news/article/kancare-not-working-for-people-with-disabilities-advocates-say
[5] Id.