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To: peoplefirstwaiver@opwdd.ny.gov

Comments on Revised Draft of New York State Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards to Serve Individuals with Intellectual and/or Developmental Disabilities in Specialized I/DD Plans – Provider Led (SIP-PL)(the "Revised SIP-PL Qualification Document")

We wrote in October 2018, on behalf of the 2200 living Willowbrook class members who are represented by the New York Civil Liberties Union ("NYCLU") and New York Lawyers for the Public Interest, co-counsel in the Willowbrook litigation,[1] to offer our comments and observations with respect to the 2018 draft SIP-PL Qualification Document.

OPWDD received extensive public comments on the 2018 draft SIP-PL Qualification Document and two years later released this revision for public comment. We believe that OPWDD has failed to fully address the concerns we (and many others) expressed in 2018.[2] We attach our initial comments submitted in October 2018 and raise these additional concerns for consideration.

OPWDD and the New York State Department of Health ("DOH") continue to ask for public comment on a document setting forth putative operator standards that are completely untethered from any publicly available information about the contours of the actual managed care environment, including how that managed care environment will be delivering managed long term supports and services ("MLTSS") to New Yorkers with I/DD. This is an entirely untenable situation. As we have noted previously, this approach suggests either the existence of a managed care system that has not been fully publicly disclosed or the future intent to create a managed care system that will deliver MLTSS to people with I/DD, completely on the fly, behind closed doors. A comprehensive managed care proposal should be released *in toto*, rather than in DOH's and OPWDD's highly fragmented and piecemeal approach.

Operating an efficient and effective MLTSS program for people with I/DD requires thoughtful program design, capable health plan partners, strong state oversight, and appropriate

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[1] *New York State Assoc. for Retarded Children v. Cuomo,* Nos. 72 Civ. 356/7 (E.D.N.Y., Hon. Raymond J. Dearie) ("Willowbrook").

[2] OPWDD has, however, now acknowledged that any SIP-PL will be responsible, with the New York State Willowbrook defendants, to comply with the entitlements afforded Willowbrook class members by the Willowbrook Permanent Injunction.

accountability mechanisms.[3] The planning, design, implementation, and evaluation processes require individuals with disabilities and their families, I/DD service providers and advocates to be able offer robust input into any systems change efforts regarding the I/DD service delivery system. Indeed, the Centers for Medicare and Medicaid Services ("CMS") requires New York State to solicit and engage with stakeholders in the development of an 1115 Waiver, including the Revised SIP-PL Qualification Document.[4]

Notwithstanding these parameters and mandates, there is still no clear articulation as to why New York State is moving OPWDD services and supports to managed care. There is nothing that assures that New York State's oversight of MCOs will ensure continued access to services and compliance with individual, and provider, protections. There is nothing that assures that New York State will define meaningful quality metrics for the I/DD population. There is still no information available as to how New York State will permit managed care organizations to operate. Managed care organizations – whether they be OPWDD provider-led or mainstream – will likely be required to reduce or otherwise limit payments they make to providers in order to remain solvent. The specific rules by which plans may engage in this pursuit when it comes to OPWDD services must be better understood by all stakeholders, including individuals with I/DD, their families and advocates and the provider communities. These are examples of only some of the deficiencies that continue to exist with respect to the Revised SIP-PL Qualification Document.

Accordingly, we urge OPWDD to pause and to reconsider the timeline and scope of the transition for people with I/DD into specialized managed care. The OPWDD service delivery system is confronting a critical shortage of staff; an inability to serve those with complex needs; a shortage of residential opportunities; a growing population of unserved and underserved; and an aging population requiring more services. The transition to managed care for people with I/DD certainly does not appear to address any of these critical systemic challenges and, indeed, may exacerbate these issues.

As both OPWDD, and DOH, are aware, the ongoing uncertain rollout of the Medicaid managed care and the "rate rationalization" system, which DOH and OPWDD negotiated with CMS have resulted in increasing uncertainty in the OPWDD service system and significant changes to the quality and range of services afforded people who require OPWDD's services. The COVID-19 pandemic has only led to further deterioration in the residential providers' fiscal circumstances and ongoing destabilization of the service delivery system.

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[3] *See 2108 MLTSS for People with Intellectual and Developmental Disabilities: Strategies for Success*, National Association of States United for Aging and Disabilities (NASUAD), http://nasuad.org/sites/nasuad/files/2018%20MLTSS%20for%20People%20with%20IDD-%20Strategies%20for%20Success.pdf. NASUAD notes that "there are several factors that make including LTSS services for people with I/DD into MLTSS programs more complex, including the length of time individuals may require services, the existence of wait lists of people who are eligible for I/DD services, and the need to design a service array that promotes and supports community integration. In addition, the provider community for individuals with I/DD is quite different than those for clinical services or for LTSS for other populations. Unlike services for older adults, there are very few private pay recipients of I/DD services, which makes I/DD providers heavily dependent on public resources. Many of the providers started from local advocacy groups, and as a result are often small organizations serving fewer than fifty people. Since services for people with I/DD are designed to engage the person fully in their community, there may be different providers for residential versus employment and day services. Moreover, their level of business acumen — ability to set prices, negotiate contracts, and meet stringent accountability outcomes demanded by MCOs — varies greatly across the country."

[4] *See* 42 CFR § 431.408.

Moreover, the OPWDD service delivery system is in the midst of a massive workforce crisis. A stable workforce of caring, competent, creative, well compensated, and qualified clinicians and Direct Support Professionals ("DSP") is critical to providing meaningful support to people with I/DD. Lack of adequate state funding has turned the complex and critical DSP role into a minimum wage job. Providers cannot compete in the employment market and lose skilled workers to venues where workers earn more and have less demanding work duties.

Finally, as OPWDD and DOH are aware, OPWDD and DOH launched an enhanced care management program in July 2018. This program consolidated more than 350 agencies providing Medicaid Service Coordination into 7 regional Care Coordination Organizations (CCOs) providing Health Home Care Management. At the same time, OPWDD expanded the role of the new care managers, moving from OPWDD service-centric Individualized Support Plans (ISPs) to an regime that is intended to integrate and coordinate health and habilitative services through an expanded Life Plan module that ties into the State's Uniform Assessment System. Approximately 100,000 individuals transitioned to the CCO model on an overly aggressive timetable. The CCO rollout has been problematic and extremely rocky at best. High staff turnover, inability to complete accurate Life Plans and to coordinate connections to services, a failure of the underlying IT support sytem, all coupled with a complete failure of advocacy on behalf of and in concert with the people with I/DD the care manager supports are the sorry hallmarks of a care management delivery system that simply fails to function as mandated.

While New York State may consider that moving the I/DD population into a managed care system will control costs and even effectuate cost savings, there is very limited data to demonstrate that implementing managed care for the I/DD population will actually produce any savings. In 2019, the Texas Health and Human Services Commission engaged Deloitte Consulting LLP ("Deloittte") to evaluate the cost-effectiveness of transitioning the Texas fee for service programs for I/DD LTSS to managed care.[5] Deloitte conducted extensive research and collection of publicly available data from other states that have experience with I/DD MLTSS to inform their assessment of the potential fiscal impacts in Texas. Deloitte concluded, amongst other things, as follows:

> While general increased access to care could decrease expenditures through improved health outcomes for members, it is not apparent that the increase in access is consistent across all populations and managed care programs. Similar to the findings on access to care, cost data on quality outcomes are not readily available and have varied results. Over the past several years, some small case studies have indicated improved quality and outcomes in managed care with care management techniques by plans. Research conducted in five states that have implemented managed care programs indicated that "anecdotal evidence suggests" savings could be realized through implementation of effective care management techniques. Limited research has been conducted with people with more complex needs, however, such as individuals with I/DD and older persons. [6]

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[5] As OPWDD and DOH are aware, Deloitte is intimately involved with New York State health actuarial services consulting.

[6] *See, e.g.*, IDD LTSS Carve-In Cost-Effectiveness Evaluation – Final Report Prepared for: Texas – Health and Human Services Commission (HHSC) HHSC Contract No. 529-15-0009-00001 | Request Number: 00021-R3

Deloitte also concluded that, based on other states' experiences, carving I/DD MLTSS services into a managed care system actually would likely result in an overall cost increase for implementing I/DD MLTSS under a managed care model -- unless, of course, services are ultimately significantly cut for people with I/DD.[7]

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Managed care strategies, singly or in combination, attempt to alter three basic factors that drive health care costs: utilization patterns, prices charged by suppliers and the share of costs borne by the insured population. Managed care strategies include risk management, utilization management, care coordination/case management gatekeeping, channeling, service substitution, bundling and health promotion. But successfully supporting people with I/DD means more than buying and selling services. It means keeping family members, friends and neighbors engaged with people with I/DD. It means maintaining and strengthening ties with communities. Managed long-term support systems must do more than contain expenditures, they must promote the efforts of people with I/DD to have valued lifestyles in their communities. Most managed care companies are used to contracting for acute health care services that are highly regulated and licensed. They are not used to contracting for services that are more tailored to the individualized needs of the long-term services and supports recipient. Managed care strategies that are based on inappropriate adaptations of health care models could effectively destroy I/DD support systems that have taken over 40 years to put into place – all without achieving any worthwhile cost efficiencies.

Furnishing long-term supports to people with I/DD simply is not the same as providing health care. The health care arena teaches us all a great deal about the architecture of managed care, but rolling out managed care for people with I/DD means the architecture must be adapted not replicated and that adaptation process must include a thorough examination of the obligations and organizations of service systems. This has still not occurred in New York State.

No information has been forthcoming for the past many years to individuals with disabilities, and their families and advocates, and they have certainly not been meaningfully consulted in connection with the ramifications of the system transformation that is underway. This situation must be redressed if the State persists in its inexorable march to managed care for this particular set of New York State citizens.

Thank you for your consideration of these comments.

s/Roberta Muller
Roberta Muller
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s/ Beth Haroules
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Senior Staff Attorney, NYCLU

Version Dated: January 11, 2019, available at https://hhs.texas.gov/sites/default/files/documents/about-hhs/communications-events/meetings-events/idd-srac/feb-2019-idd-srac-agenda-item-2.pdf, at pg. 16.

[7] *Id.* at 7-10, 63-96.

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To: peoplefirstwaiver@opwdd.ny.gov

Comments on Draft of New York State Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards to Serve Individuals with Intellectual and/or Developmental Disabilities in Specialized I/DD Plans – Provider Led (SIPs-PL)(the "Proposed SIPs-PL Plan")

We write, on behalf of approximately 2,600 living Willowbrook class members who are the clients of the New York Civil Liberties Union ("NYCLU") and New York Lawyers for the Public Interest, co-counsel in the Willowbrook litigation,[1] to offer comments and observations with respect to the Proposed SIPs-PL Plan. Willowbrook class members range in age from 42 to 100+ and live in each and every region of New York State from the tip of Long Island to the North Country and west to Western New York. The Willowbrook class members receive services in both state-operated settings and in the voluntary-operated settings. We offer first our comments relating to the process relating to the release of the Proposed SIPs-PL Plan; we then provide comments on several substantive issues presented by the Proposed SIPs-PL Plan.

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[1] In 1972, the NYCLU, with others, commenced the Willowbrook case, a class action litigation in the United States District Court for the Eastern District of New York in 1972, charging that the State of New York had violated the constitutional rights of the residents of the Willowbrook State School. That action, bearing the caption *New York State Assoc. for Retarded Children v. Carey*, Nos. 72 Civ. 356/7, 393 F. Supp. 715 (E.D.N.Y. 1975) (hereinafter the "Willowbrook litigation"), is still pending in the United States District Court before the Hon. Raymond J. Dearie. The Willowbrook litigation was in the vanguard of the civil rights movement for people with disabilities. Well before the *Olmstead* decision issued by the United States Supreme Court in 1999, the Willowbrook consent judgment mandated that individuals with intellectual disabilities be afforded the "least restrictive and most normal living conditions possible." This represented a seismic move away from a medical model of care with a robust focus on active treatment, community inclusion, and true quality of life for people with I/DD

I. Process Points relating to the Release of the Proposed SIPs-PL Plan

This document purports to describe the qualifications for applicants to form SIP-PLs, the specialized managed care plans that are to be "controlled" by provider organizations in the OPWDD system with a history of serving New Yorkers with intellectual and/or developmental disabilities (I/DD).[2] The draft Proposed SIPs-PL Plan establishes special requirements for "Early Adopter" plans for developing and operating a SIP-PL.[3] But it does not outline the so-called "operational requirements …for a plan […] engaging in coordinated care for individuals with I/DD."[4] Those operational requirements apparently will be set forth in a "policy document" which will not become available for public comment until the "first quarter of 2019." [5] Subsequently, the Proposed SIPs-PL Plan states, the final transition to managed care "will be described in amendments to the Comprehensive HCBS Waiver and the MRT 1115 Waiver."[6]

OPWDD and DOH are currently asking for public comment on a document setting forth putative operator standards that are completely untethered from any publicly available information about the contours of the actual managed care environment, including how that managed care environment will be delivering managed long term supports and services ("MLTSS") to New Yorkers with I/DD. This is an entirely untenable situation. This approach seems to suggest either the existence of a managed care system that has not been fully publicly disclosed or the future intent to create a managed care system that will deliver MLTSS to people with I/DD,

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[2] It is not entirely accurate to suggest, as OPWDD appears to, that the SIPs-PL will actually be run by NYS I/DD providers. From a corporate perspective, "control" means that an entity, or group of entities, exercises at least 51% of the voting rights of the corporate entity. It is entirely possible, even likely given the New York State Public Health Article 44 reserve cash requirements, that a SIPs-PL will be comprised of several NYS I/DD provider entities, as the CCO/HHs are currently configured, collectively comprising 51%, partnering with one non-I/DD familiar/experienced managed care entity comprising the remaining 49%. In this scenario, the managed care entity will actually exercise *de facto* "control" over the I/DD provider members of the SIPs-PL.

[3] The term "Early Adopter" refers to I/DD-led organizations that are approved to operate a New York State Public Health Law Article 44 Medicaid Managed Care Plan. According to OPWDD, these "[e]arly adopters began almost a year ago to apply to become a mainstream managed plan. These are entities that are committed to becoming a mainstream managed care plan as a first step in the process of becoming a specialized I/DD plan." *See Stakeholder Summary:Managed Care Qualification Document Presentation, Transcript*, https://opwdd.ny.gov/sites/default/files/documents/Stakeholder%20Summary%20Qual%20Document%20Video%20Transcript%20Final.pdf.

This is an extraordinary statement. Clearly OPWDD, and presumably, the New York State Department of Health ("DOH") have been working with managed care provider entities over the past year to structure the SIPs-PL and to formulate the managed care regimen that New Yorkers with I/DD are to be thrust into. Yet OPWDD has taken the position that there is no operative policy documents that are ready for stakeholder review. "The policy document is the next step that defines what the plans will do and more closely relates to the person's experience in the managed care plan. That document will be available in the first quarter of 2019 and that's really where we delve into matters that will be of interest for stakeholders who are interested in learning about the SIP-PL opportunity." *Id.*

It would be useful to know precisely which Early Adopters have been working for the past year on their SIPs-PL applications and whether these Early Adopters are currently any of the CCO/HH entities, or not. It would also be useful to know which mainstream managed care organizations are participating in partnership with I/DD providers as Early Adopters.

[4] *Id.*

[5] *Id.*

[6] *See* Proposed SIPs-PL Plan at p.5.

completely on the fly, behind closed doors. A comprehensive managed care proposal should be released *in toto*, rather than in DOH's and OPWDD's highly fragmented and piecemeal approach.

Operating an efficient and effective MLTSS program for people with I/DD requires thoughtful program design, capable health plan partners, strong state oversight, and appropriate accountability mechanisms.[7] The planning, design, implementation, and evaluation processes require individuals with disabilities and their families, I/DD service providers and advocates to be able offer robust input into any systems change efforts regarding the I/DD service delivery system. Indeed, the Centers for Medicare and Medicaid Services ("CMS") requires New York State to solicit and engage with stakeholders in the development of an 1115 Waiver, including the Proposed SIPs-PL Plan.[8]

None of this has happened here. It appears that the only "stakeholders" OPWDD and DOH have consulted have been the private providers.[9] Individuals with I/DD, their family and advocates, representatives of self-advocacy and disability rights organizations, and the other organizations or agencies that represent the rights and interests of people with disabilities in New York State should have been involved in, but have largely been excluded from, fundamental planning and structuring of the New York State MLTSS system for people with I/DD.[10]

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[7] *See 2108 MLTSS for People with Intellectual and Developmental Disabilities: Strategies for Success*, National Association of States United for Aging and Disabilities (NASUAD), http://nasuad.org/sites/nasuad/files/2018%20MLTSS%20for%20People%20with%20IDD-%20Strategies%20for%20Success.pdf. NASUAD notes that "there are several factors that make including LTSS services for people with I/DD into MLTSS programs more complex, including the length of time individuals may require services, the existence of wait lists of people who are eligible for I/DD services, and the need to design a service array that promotes and supports community integration. In addition, the provider community for individuals with I/DD is quite different than those for clinical services or for LTSS for other populations. Unlike services for older adults, there are very few private pay recipients of I/DD services, which makes I/DD providers heavily dependent on public resources. Many of the providers started from local advocacy groups, and as a result are often small organizations serving fewer than fifty people. Since services for people with I/DD are designed to engage the person fully in their community, there may be different providers for residential versus employment and day services. Moreover, their level of business acumen — ability to set prices, negotiate contracts, and meet stringent accountability outcomes demanded by MCOs — varies greatly across the country."

[8] *See* 42 CFR § 431.408.

[9] The OPWDD website page is literally named "Managed Care for Providers." *See* https://opwdd.ny.gov/providers_staff/managed_care/providers. The Proposed SIPs-PL Plan, as well as the "presentation to outline the document for easier understanding," which links to a youtube.com posting, and the transcript of that video presentation are all located on that "Managed Care for Providers" page.

[10] In this regard, we note that OPWDD's Transformation Panel, which OPWDD has identified as the source of the recommendations to transition from the HCBS 1915 b/c waiver program to managed care under an 1115 waiver, had two parents of individuals with developmental disabilities and only one self-advocate and direct stakeholder as members of that panel. *See* https://opwdd.ny.gov/opwdd_about/commissioners_page/transformation-panel. And, the Transformation Panel has not performed any work on the managed long term care system, at least any work that has been publicly disclosed.

Similarly, OPWDD has indicated that since April 2013, a Joint Advisory Council has been advising OPWDD and DOH regarding the design of managed care models that will provide services to individuals with developmental disabilities, but their input as publicly reported appears to have been limited to the Fully Integrated Duals Advantage (FIDA-IDD) and the Program of All Inclusive Care for the Elderly (PACE) model. There is one self-advocate and one representative of an Independent Living Center on the JAC. *See* https://opwdd.ny.gov/opwdd_services_supports/people_first_waiver/opwdd-joint-advisory-council-managed-care. It would not appear from the JAC meeting minutes that they are actively involved in any work developing, much less

We further note that the Proposed SIPs-PL Plan is a 92-page highly technical, jargon-filled document that is rendered in English only[11] and that is available only via Internet. The explanatory youtube.com powerpoint presentation and the transcript of that youtube.com powerpoint are also rendered in English only and present, effectively, an oversimplified and non-informative recapitulation of the table of contents of the Proposed SIPs-PL Plan. There have been no public hearings on the Proposed SIPs-PL Plan.[12] The Proposed SIPs-PL Plan, in a number of places, incorporates by reference the MMC Model Contract.[13] It is inappropriate to merely incorporate by reference certain provisions of the MMC Model Contract. Those applicable provisions and requirements, including any grievance, appeal, and fair hearing processes, must be detailed in the Proposed SIPs-PL Plan so that it is clear to all readers what provisions of the MMC Model Contract will be applicable to the SIPs-PL.

As we have indicated in previous comments on a number of OPWDD and DOH initiatives revealed in piecemeal fashion over the past several years, OPWDD is obligated to communicate, meaningfully with LEP individuals as well as individuals who are "visually limited or have limited reading proficiency," "deaf or hard of hearing" who cannot read and people "without speech capacity who use alternative means of communication." That clearly has not happened with respect to the Proposed SIPs-PL Plan.

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commenting on the Proposed SIPs-PL Plan or OPWDD's managed care service system. As but one example, the June 2018 meeting minutes state as follows: "Lastly, Allison briefly discussed key components of the Specialized I/DD Plan (SIP-PL) Qualifications documents and discussed the specific areas that the OPWWD is seeking input from the Council. Council members requested that this topic be first on the agenda for the next meeting." *See* https://opwdd.ny.gov/sites/default/files/documents/Approved_JAC_Meeting_Minutes_6-14.18.pdf. The JAC's "next meeting" was held on September 13, 2018. While no minutes are yet available from that meeting, the agenda and powerpoint for that meeting indicates that the " NYS Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards" and the Proposed SIPs-PL Plan was to be discussed at that meeting, well after the Proposed SIPs-PL Plan had already been released for public comment.

[11] This is a violation of MHL 13.09(e) and 14 NYCRR 633.4(15) as well as Executive Order 26 (10/6/2011). This also appears to violate both OPWDD's and DOH's Language Access Plan(s) For Limited English Proficient Individuals. OPWDD's Language Access Plan is available at https://dhr.ny.gov/sites/default/files/pdf/lep/OPWDD%202016%20Language%20Access%20Plan.pdf ("OPWDD determined **vital documents to be information about supports and services**, and documents that require consent. These forms are available in Spanish, Chinese, Russian, Korean, Urdu, Haitian Creole, Italian, and Yiddish, and are posted on the Language Access public Website and on the internal Intranet pages for State employees and not-for-profit licensed providers.")(emphasis supplied). DOH has a similar Language Access Policy available at https://dhr.ny.gov/sites/default/files/pdf/lep/DOH%202016%20Langauge%20Access%20Plan%20signed.pdf ("Documents determined to be vital include intake and consent forms; **notice of rights, requirements and responsibilities; and such others that contain pertinent information to assist in accessing program benefits.**")(emphasis supplied).

[12] We understand that "OPWDD will also be holding public forums in the coming months to discuss managed care more generally and these will include the opportunity to talk about how to support community living, personal control and employment and support for family caregivers through the managed care development process." *See* https://opwdd.ny.gov/sites/default/files/documents/Stakeholder%20Summary%20Qual%20Document%20Video%20Transcript%20Final.pdf. But those public hearings will be to discuss the managed care environment that OPWDD and DOH have already fully designed and plan to launch as early as August 2019.

[13] *See e.g.* SIPs-PL "must meet[] all requirements in the MMC Model Contract unless otherwise stated." Proposed SIPs-PL Plan at 19.

There is, moreover, as we have repeatedly noted, a very real digital divide in New York State. There are actual inequalities between individuals, households, and other groups of different demographic and socioeconomic levels in access to information and communication technologies and in the knowledge and skills needed to effectively use the information gained from connecting. Not everyone in NYS has online access or fluency. There must be alternative avenues provided to ensure accountability and access to information, pricing, services beyond "portals" and efforts by OPWDD to increase transparency, beyond ensuring the OPWDD public website includes regular updates of overall services that are being provided to individuals, and the number of new individuals receiving such services.

At bottom, we agree fully with the New York State Protection and Advocacy system Disability Rights New York's assessment that the Proposed SIPs-PL Plan, "as well as the entire transition to managed care, is so unwieldy and unclear that most people with intellectual and/or developmental disabilities and their families and advocates are unaware of the magnitude of changes to come. They are therefor unable to meaningfully understand the transition to managed care"[14] or even comment on that proposed system.

II. Substantive Comments on the Proposed SIPs-PL Plan

The Proposed SIPs-PL Plan conveys very little information of substance regarding the implementation of managed care for people with developmental disabilities. The patent lack of detail around the managed care environment and the provision of MLTSS obviously makes it difficult to offer meaningful commentary at this point in time. We look forward to commenting further on a more substantive and comprehensive managed care plan. That being said, we can offer the following overarching comments on New York State's latest effort to cohort people with I/DD into a managed care environment as follows.

1. The Willowbrook Litigation

New York State is responsible for ensuring certain entitlements under the Willowbrook Permanent Injunction, including protection from harm and high quality, community-based integrated services, to be provided in the least restrictive setting and regardless of any Willowbrook Class Member's inability or failure to pay a fee or a Willowbrook Class Member's ineligibility for Medicaid. The Proposed SIPs-PL Plan is completely silent with respect to responsibility of the SIPs-PLs to be both cognizant of and compliant with the Willowbrook Permanent Injunction.

2. Due Process Concerns

The Proposed SIPs-PL Plan lacks sufficient detail on due process protections and fails to set forth the process for appealing an adverse decision, initiating an objection, or requesting a Medicaid fair hearing. If, as we understand it, the provisions of the MMC Model Contract relating to the grievance, appeal, and fair hearing process will govern, those provisions are fundamentally

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[14] *See DRNY Comments on Draft of New York State Medicaid Managed Care Organization I/DD System Transformation Requirements and Standards to Serve Individuals with Intellectual and/or Developmental Disabilities in Specialized I/DD Plans – Provider Led (SIPs-PL),* dated October 3, 2018 at 1.

different and less protective than the due process protocols currently in place in the OPWDD system[15] and appear generally to require exhaustion of a SIPs-PL internal appeals process and the NYS Insurance Department "external appeal" process. The fair hearing process appears to relate only to denial, reduction or termination of coverage for a medical service. The MMC Model Contract process also posits a lesser complaint process to address "problems or disputes with […] care or services" that can be pursued either directly with the plan or with DOH. It is unclear how the MMC Model Contract complaint, grievance, appeal and fair hearing provisions relate, or not, to MLTSS services for people with I/DD and whether OPWDD has any role, or no role, with respect to due process issues.[16]

With respect to SIPs-PL disenrollments, the Proposed SIPs-PL does not demonstrate compliance with the mandates of 42 CFR 438.56(b). The Proposed SIPs-PL Plan does not:

> (1) Specify the reasons for which the [SIPs-PL] may request disenrollment of an enrollee.
>
> (2) Provide that the [SIPs-PL] may not request disenrollment because of an adverse change in the enrollee's health status, or because of the enrollee's utilization of medical services, diminished mental capacity, or uncooperative or disruptive behavior resulting from his or her special needs (except when his or her continued enrollment in the [SIPs-PL] seriously impairs the entity's ability to furnish services to either this particular enrollee or other enrollees).
>
> (3) Specify the methods by which the [SIPs-PL] assures the agency that it does not request disenrollment for reasons other than those permitted under the contract.

3. Medical Necessity Standards and Utilization Protocols

The broad-based application of managed care to people with I/DD is still largely uncharted territory. There is nothing set forth in the Proposed SIPs-PL Plan that demonstrates how managed health care approaches will be applied to the provision of long-term supports and services systems to this particular Medicaid population. And the Proposed SIPs-PL Plan is entirely silent on how the managed health care approaches undertaken by New York State already with respect to other Medicaid populations will in fact be applied to the I/DD MLTSS system.

Managed health care is anchored by sanctioned practice standards and care and medical necessity criteria. In many long-term support systems, there are competing practice standards and care criteria. In the absence of any agreement concerning practice standards and care criteria, it is virtually impossible to adapt conventional managed health care models, where care criteria define plan obligations, to the provision of long-term supports and services.

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[15] Pursuant to 14 NYCRR § 633.12, individuals receiving services in the OPWDD system may initiate an objection "related to facilities or HCBS waiver services […] regarding: (i) any plan of services […] or part thereof and proposed changes thereto; (ii) plans for placement […], (iii) a proposal initiated by the agency/facility to discharge […]; and (iv) a proposal to reduce, suspend or discontinue HCBS waiver service(s)."

[16] *See New York State Medicaid Managed Care Model Member Handbook* at 5-15, https://www.health.ny.gov/health_care/managed_care/docs/medicaid_managed_model_member_handbook.pdf.

SIPs-PL are required to use New York's "medical necessity" standard for utilization management.[17] Utilization management is employed to ensure that services are necessary, efficacious and the least costly available. Clearly, any utilization management standards that will be approved by DOH and OWDD must be standardized and public. But, clinically-defined managed care approaches do not align well with the support delivery process for people with I/DD which weaves together housing, work, participation in community activities and related areas of community living. How do OPWDD and DOH intend that the SIPs-PL will assess precisely how supportive housing services, work, participation in community activities and related areas of community living will "correct or cure" a person with I/DD? In its utilization management reviews, how do OPWDD and DOH intend that the SIPs-PL assess the "medical necessity, appropriateness, and efficiency of the use of" MLTSS services by a person with I/DD?

The Proposed SIPs-PL Plan must detail the protocol for the SIPs-PL to "review and approv[e] of Life Plans inclusive of HCBS Waiver services."[18] Can the SIPs-PL alter, diminish, reduce or eliminate services set forth in an appropriately formulated Life Plan? Will any of those actions by SIPs-PLs entitle a person to notice and due process rights including a formal appeals process?

The Proposed SIPs-PL mandates that "[w]hen an individual no longer meets [medical necessity criteria] for a specific service, the SIP-PL should work with the individual's provider to ensure that an appropriate new service is identified (if needed), necessary referrals are made, and the enrollee successfully transitions without disruption in care."[19] What are the responsibilities of the SIPs-PL in these contemplated circumstances ? What is a person's recourse if the SIPs-PL fails to meet its responsibilities or worse, determines to alter, diminish, reduce or eliminate a person's services? Will any of those actions by SIPs-PLs entitle a person to notice and due process rights, including a formal appeals process?

4. Role of OPWDD, the DDROs and DDSOs in the SIPs-PL Environment and Regulatory Overlay Applicable to SIPs-PLs

There is a fundamental lack of clarity regarding the role of OPWDD, the DDROs and the DDSOs in the SIPs-PL environment. The DDROs host the Residential Opportunities Committee which assesses residential placement determinations and the DDROs host the Front Doors which process eligibility determinations and connect people to available services. The DDSOs are often times the provider of last resort with respect to people with complex needs, whether they are behavioral, medical, forensic or quasi-forensic needs. Will the SIPs-PLs be mandated to contract with the DDSOs for continuation of these types of services? The Proposed SIPs-PL Plan is also silent with respect to whether or not state-funded services will continue to be available to people

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[17] *See* Proposed SIPs-PL Plan at 36. *See also* Definitions at 16: "Medical Necessity: New York law defines 'medically necessary medical, dental, and remedial care, services, and supplies' in the Medicaid program as those "necessary to prevent, diagnose, correct, or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person's capacity for normal activity, or threaten some significant handicap and which are furnished an eligible person in accordance with state law" (N.Y. Soc. Serv. Law, § 365-a). "Utilization Management (UM): The evaluation of the medical necessity, appropriateness, and efficiency of the use of health care services, procedures, and facilities under the provisions of the applicable MMCP."

[18] *See* Proposed SIPs-PL Plan at 37.

[19] *See* Proposed SIPs-PL Plan at 36.

who are not HCBS-eligible, including Willowbrook class members and others who are living in SNFs or other rehabilitation settings, pending a return to a community-based setting.

The Proposed SIPs-PL Plan is also largely silent as to the regulatory requirements applicable to SIPs-PLs. The SIPs-PLs are not "under the jurisdiction of OPWDD," thus are the SIPs-PLs subject to any OPWDD regulations?[20] For example, does 14 NYCRR 624 apply to SIPs-PLs and will SIPs-PLs be subject to the jurisdiction of the Justice Center? Do none of the other provisions of 14 NYCRR 633 with regard to safety and prevention of abuse apply to persons receiving SIPs-PL services, including in particular 14 NYCRR 633.16 as that section relates to person-centered behavioral intervention/behavioral support plans? What about 633.7 and 633.8 Conduct of employees, volunteers, family care providers and custodians/Training, 633.10 Care and Treatment, 633.11Medical Treatment, 633.12 Objection to Services, 633.13 Research, 633.17 Medication [particularly with an eye to freedom from chemical restraints], 633.18 DNR orders and 633.20 Health Care Proxies. This raises a larger question as to whether or not a person receiving services in the SIPs-PL network will be deemed to be people receiving services for purposes of SCPA 1750-b end of life decision-making or whether people under the SIPs-PL networks will be covered by the Family Health Decision Act under NYS Public Health Care Law?

5. Rate Setting and Reserve Setting Provisions

The Proposed SIPs-PL Plan is completely silent as to how capitated rates will be set for the SIPs-PL other than to say that they will be "actuarially sound." Details regarding the rates and how they will be set must be disclosed. And, ultimately, DOH and OPWDD must set the capitated rates sufficiently high or 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.

In this regard, the Proposed SIPs-PL Plan contains no information on the InterRai Coordinated Assessment System ("CAS") and the role it will play with respect to eligibility screening, acuity setting and how it will impact the amount or type of services that an individual is entitled to access. It is fair to state that we are all well aware that the CAS is intended to provide a way in which OPWDD can equitably allocate services based upon the person's need as outlined by the Commissioner's Transformation Panel and inform the person-centered planning process and development of the person-centered service plan (i.e. the LifePlan). But the Proposed SIPs-PL Plan does not explain how and when individuals will be informed of their CAS score and what procedural protections are available to individuals who wish to contest their results. The Proposed SIPs-PL Plan does not set out the timeline for implementation of the CAS statewide.

The Proposed SIPs-PL Plan is silent as to what risk adjustment features are to be employed with respect to people with I/DD. Capitation generally gives MMMC plans incentives to

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[20] The Proposed SIPs-PL Plan indicates that "During the transition to Managed Care, the current oversight, incident reporting requirements and quality standards for OPWDD state and voluntary-operated State Plan and HCBS services will not change significantly." *See* Proposed SIPs-PL Plan at 7. The Proposed SIPs-PL also notes that "OPWDD Division of Quality Improvement (DQI) will continue its surveillance and survey of programs and services under the auspices of OPWDD." *Id.* This suggests that OPWDD DQI will not be involved with oversight of the SIPs-PL. Will oversight of the SIPs-PL rest merely with DOH?

underserve heavy users of health care services. All of the I/DD services set forth in the Proposed SIPs-PL Plan are coming in at FFS rates which presumably have been frozen in the current system of "rate rationalization," but are then to be converted with 24 months of enrollment into managed care becoming mandatory, into some sort of risk payment arrangement (e.g. risk corridor or stop/loss arrangement). When and how do DOH and OPWDD intend to determine the methodology for setting capitation rates for these services and based on what experience in delivering these services ?

A "full risk" approaches place a high premium on the service provider controlling their own costs and are fraught with the potential for creating incentives for the provider to cut corners. Will DOH and OPWDD have any ability to determine whether and when the systemic reaction to risk management strategies with the I/DD service providers compromises the quality and accessibility of care, with any ability to mitigate such compromise?

The Proposed SIPs-PL Plan speaks to certain guaranteed payments which a "[SIPs-PL] provider may waive …to participate in advanced –level VPB strategies at an earlier date."[21] Yet the Proposed SIPs-PL Plan is silent as to what participation, if any, the actual recipient of services may be entitled to with respect to the provider's decision to participate in such "advanced level VPB strategies" at an earlier date?

The Proposed SIPs-SL Plan finally establishes certain reserve requirements for SIPs-PLs.[22] It is not possible to comment on the adequacy of the contingent reserve requirements and escrow funds, including whether or not the reserve requirements actually bar I/DD providers from participating as a SIPs-PL without significantly more data.

6. Value Based Payment Reform Program and People with I/DD

The Proposed SIPs-PL Plan indicates that the I/DD managed care system will operate under the NYS Value Based Payment Reform Program ("VBP") yet there is still no real indication as to the quality measures and markers that will serve as the basis of the VBP model as applied to the I/DD program.

The VBP program has not been adapted for people with I/DD and the process undertaken to date in order to developing data driven VBP I/DD quality measures was not, in fact, guided by stakeholders because the data metrics recommended in the I/DD CAG Report are not appropriate to people with I/DD. The quality recommendations contained in the I/DD CAG rest on almost purely health-oriented requirements, which do little to improve the quality or appropriateness of I/DD supports. The use of a medicalized set of VBP quality measurements simply fails to give adequate weight to the well-developed quality of life measures in which the entire I/DD system and OPWDD's vast array of providers have invested for so many years. The VBP model proposed

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[21] "Initially, these services will be subject to levels zero (0) through two (2) VBP and will be paid via a Fee-For-Service pass through, at the State Medicaid rate, with opportunities for shared savings for the achievement of quality outcomes. no later than twenty-four (24) months after the implementation of mandatory enrollment, the OPWDD HCBS Waiver services and OPWDD residential services will be placed in capitated premium rates]. *See* Proposed SIPs-PL Plan at 11.

[22] *See* Proposed SIPs-PL Plan at 51. The enabling statute for specialized Managed Care for the I/DD population did not specify reserve requirements. *See* Public Health Law § 4403-g.

in the I/DD CAG Report not only fails to "value" quality of life markers but also creates the very real danger that "costly" individuals, such as people with I/DD who require more than minimal care and who will not "improve" or need fewer hours of care over time, will be relegated to nursing homes and other agencies that are not required to provide enough staffing or programming because the rates are not designed to reward agencies that provide a better quality of life for consumers as opposed to simply a reduction of Medicaid costs for New York State.

Absent any connection between OPWDD quality assurance/quality improvement data and the recommended measures set forth in the I/DD CAG Report, agencies that provide bad care that does not result in hospitalization and/or other medical utilization could wind up achieving high monetary VBP compensation than agencies that provide quite good "total population care" but whose consumers have higher rates of medical utilization.

7. Community First Choice Option ("CFCO") Services

OPWDD and DOH have aligned the service limits of the NYS State Plan (SPA) # 13-0035, or the CFCO plan, with OPWDD's HCBS waiver plan provisions relating to certain supports and services routinely provided to individuals in need of long term care. Such supports and services include, but are not limited to, Community Habilitation, Environmental Modifications ("E-mods"), Vehicle Modifications ("V-mods"), Assistive Technology, Community Transition Services, and "Social Transportation."[23] The State Plan CFCO is operated under the auspices of the DOH, not OPWDD.

OPWDD had previously negotiated the limits to items such as Environmental Modifications by reviewing historic billing levels and determining a level that would not diminish services for waiver recipients. The caps on services in comparable NYS waivers, such as those now managed by DOH, are noticeably lower than the previous OPWDD limits.[24] The limits on E-mods have dropped from $60,000 per person in any five year window to $15,000 per person in any five year window. The limits on adaptive technology have dropped from $35,000 per person in any two year window to $15,000 per person in any two year window; technology or devices that cost in excess of $1000 can only be procured after the submission of three bids to NYS.[25]

The Proposed SIPs-PL Plan does not provide any direction on how the SIPs-PLs will avoid:

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[23] *See* Amendment 01, Appendix C at 73-76, 84-87, 90-92, 104-106 and Addendum A at 362-364. *See also* NYS DOH CFCO webpage at https://www.health.ny.gov/health_care/medicaid/redesign/community_first_choice_option.htm.

[24] *See Response to Public Comment on the OPWDD Comprehensive Home and Community Based Services (HCBS) Waiver Renewal and the New York State OPWDD Home and Community Based Settings Transition Plan Response to Public Comments* at 12 Q.2, available at https://www.opwdd.ny.gov/sites/default/files/documents/ResponseToPublicCommenOnTheOPWDDComprehensiveWaiver.pdf.

[25] V-mods were previously encompassed within the adaptive technology ambit; V-mods will now be offered as a separate service subject to a $15,000 cap; the modifications are limited to only the principal vehicle used by the individual. There is no indication if there is a lifetime cap or whether there are any other timeframes governing this service. The cap on one time payments for community transition assistance is being lifted from $3000 to $5000.

a. supports and services being eliminated/reduced due to the reduction in the amounts of the overall caps imposed on these supports and services administered by DOH;

b. delay in supports and services being provided due to the necessity of multiple bids needing to be received by DOH before authorization is provided for those supports and services; and/or

c. supports and services being eliminated, reduced or delayed due to the necessity of a person demonstrating the "medical necessity" required to bypass the "soft caps" that CFCO will impose on supports and services.[26]

8. Network Requirements in Case of Insufficient County Providers

Long term support systems in New York State too often have few suppliers and may not yield the same degree of saving that have occurred in managed health care. Managed health care saving stem in part from the fact that the health care marketplace is highly competitive and has excess supply. In community support systems in New York State, the opposite is true.

The Proposed SIPs-PL Plan states each SIPs-PL will contract with at least two HCBS provider agencies to deliver HCBS services in each county.[27] Where there is insufficient network capacity in a county, the SIPs-PL must contract with a provider in a neighboring county. If network capacity is still insufficient then the SIPs-PL must contract with a provider in another Developmental Disabilities Regional Office ("DDRO"). The Proposed SIPs-PL Plan posits as an example that if someone lives in Rensselaer County and cannot obtain services from a provider within the Capital DDRO region, the SIPs-PL must contract with a provider in Sunmount or Hudson Valley, or any combination of regions, to provide service. This example reveals a deep unfamiliarity with the characteristics of many people with I/DD. Why would DOH and OPWDD assume that it would be appropriate for a person with I/DD to travel two or three hours each way to access services in an adjoining but geographically distant region? Similarly, why would DOH and OPWDD assume that a service provider would be willing and able to send staff on extended travel trips to deliver services to a persons in a neighboring but distant county or region? OPWDD and DOH must increase service delivery capacity and ensure that each county has at least two providers to deliver HCBS services.

It is also particularly important that there be adequate network affiliated clinical providers. Meeting the health needs of a person with I/DD often requires greater involvement on the part of caregivers plus an allowance of significant amounts of time for office visits. Many people with I/DD have longstanding relationships with clinicians who know the person's medical history well and who are willing to provide services to people with I/DD. Managed care may reduce or

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[26] "Medical necessity" as defined in NYS Social Services Law § 365-a(2) sets a very high bar of proof. "Standard coverage" shall mean payment of part or all of the cost of medically necessary medical, dental and remedial care, services and supplies, as authorized in this title or the regulations of the department, which are **necessary to prevent, diagnose, correct or cure conditions in the person that cause acute suffering, endanger life, result in illness or infirmity, interfere with such person's capacity for normal activity, or threaten some significant handicap** and which are furnished an eligible person in accordance with this title and the regulations of the department. [emphasis supplied].

[27] *See* Proposed SIPs-PL Plan at 74.

eliminate access to preferred health care providers if those health care providers are not affiliated with the new managed care plan.[28] We have seen that situation occur already for those people who are dually eligible for Medicare and Medicaid who want to participate in the FIDA/IDD PHP plan. Once NYS permits SIPs-PLs to come on-line, these access issues are likely to increase. Will there be any "point of service" aka "out of network" options built into the SIPs-PL Plans so that people can obtain care outside the managed care plan in which they are enrolled? Will the plans be required to sign up "any willing provider"? Will there be mandated essential community provider obligations imposed on these managed care plans?

9. "Social Transportation," Religious and Recreational Activities

Attachment K to the Proposed SIPs-PL Plan indicates that "social transportation" will be an SIPs-PL service under the CFCO system currently in place yet fails to specify how an individual will access this type of service as it is not currently offered as an HCBS service to individuals with I/DD.

The Proposed SIPs-PL Plan is also entirely silent as to how an individual will access religious and recreational activities under the SIPs-PLs.

10. Out of State Personnel Positions and Functions of the SIPs-PL

Attachment C of Proposed SIPs-PL Plans indicates that many of the "Key Personnel" of the SIPs-PL are NOT required to be based in New York State.[29] The Proposed SIPs-PL Plan does not offer any rationale as to why these positions are permitted to be located remotely, much less how OPWDD and DOH will ensure these personnel are trained to understand New York State's Medicaid system and local resources and challenges. Similarly, the Proposed SIPs-PL Plan permits Member Services call centers to be place out-of-state so long as customer service representatives are "adequately trained on all New York State requirements."[30] The Proposed SIPs-PL Plan does not define "adequately trained" and does not explain how DOH and OPWDD will implement and ensure the adequacy of the training.

11. New York State's Section 1115 Medicaid Waiver Amendment for I/DD Evaluation Criteria

The Proposed SIPs-PL Plan still does not make clear how New York State's Section 1115 Medicaid Waiver Amendment for I/DD is consistent with the relevant goals and criteria against which Section 1115 waivers must be measured. The Proposed SIPs-PL Plan sets forth no formal research methodology involving, for example, control/study group assessments; the transition will be implemented on a statewide basis and is to be, effectively, a permanent transition of people with I/DD into a mandatory Medicaid managed care environment.

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[28] The Proposed SIPs-PL Plan states that individuals will be allowed to continue with their medical providers only for 24 months following enrollment for episodes of care that were ongoing during the transition. *Id.* at 33.

[29] Those positions include ID/DD Dental Coordinator, ID/DD Utilization Management Director, Member Services Director, Quality Management Director, Information Systems Director, Utilization Management, Clinical Peer Reviewers, Quality Management Specialists and Provider Relations. *See* Proposed SIPs-PL Plan at 23-28 and Appendix C.

[30] *See* Proposed SIPs-PL Plan at 28.

The Social Security Act requires a section 1115 waiver to be limited to an experimental, pilot, or demonstration project of limited scope and duration.[31] As we have noted before, it appears to us that the Proposed SIPs-PL Plan and the Proposed 1115 Waiver Request represent nothing more than an overhaul of the New York State Medicaid program to cut the costs incurred by the State in providing services to people with I/DD.

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Managed care strategies, singly or in combination, attempt to alter three basic factors that drive health care costs: utilization patterns, prices charged by suppliers and the share of costs borne by the insured population. Managed care strategies include risk management, utilization management, care coordination/case management gatekeeping, channeling, service substitution, bundling and health promotion. But successfully supporting people with I/DD means more than buying and selling services. It means keeping family members, friends and neighbors engaged with people with I/DD. It means maintaining and strengthening ties with communities. Managed long-term support systems must do more than contain expenditures, they must promote the efforts of people with I/DD to have valued lifestyles in their communities. Most managed care companies are used to contracting for acute health care services that are highly regulated and licensed. They are not used to contracting for services that are more tailored to the individualized needs of the long-term services and supports recipient, according to the agency. Managed care strategies that are based on inappropriate adaptations of health care models could destroy I/DD support systems that have taken over 40 years to put into place without achieving any worthwhile cost efficiencies.

Furnishing long-term supports to people with I/DD simply is not the same as providing health care. The health care arena teaches us all a great deal about the architecture of managed care, rolling out managed care for people with I/DD means the architecture must be adapted not replicated and that adaptation process must include a thorough examination of the obligations and organizations of service systems. This has still not occurred in New York State.

A final comment about the process that DOH and OPWDD have engaged in this inexorable roll out of the managed care system for people with I/DD. The roll out of information has come in an extraordinarily convoluted and fractured fashion. OPWDD has revealed that it has been working closely for the past year with "Early Adopters" in connection with the SIPs-PL

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[31] At the time of its enactment, Congress described section 1115 as a way to "test out new ideas and ways of dealing with the problems of public welfare recipients." Congress has stated that demonstration projects "usually cannot be statewide in operation" and "are expected to be selectively approved by the Department." S. R. No. 1589, 87th Cong, 2d Sess. 19-20 (1962). See also H.R. No. 1414, 87 Cong., 2d Sess. (1962). It is important to note that the statute was not enacted to enable states to save money or to evade federal requirements but to "test out new ideas and ways of dealing with the problems of public welfare recipients." *Beno v. Shalala*, 30 F.3d 1057, 1069 (9th Cir. 1994)(citing S.Rep. No. 1589, 87th Cong., 2d Sess. 20, reprinted in 1962 U.S.C.C.A.N. 1943, 1961). The 9th Circuit further cautioned that while a State "may well contemplate experiments which aim to determine whether a certain reform will save money…a simple statewide benefits cut is not, in and of itself, an experiment designed to determine whether the [Medicaid] program might be run more efficiently. The immediate fiscal impact of reducing benefits is obvious, and such a benefits cut does not constitute an experiment unless data is collected, some other reform is implemented, or the program has some legitimate research component." 30 F.3d at 1069 n.30.

application process. No information has been forthcoming for the past many years to individuals with disabilities, or their advocates, and they have certainly not been meaningfully consulted in connection with the ramifications of the system transformation that is underway.

Thank you for your consideration of these comments.

s/Roberta Muller	*s/ Beth Haroules*
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