

From: [REDACTED]
To: doh.sm.1115Waivers
Subject: 1115 Public Forum (11.29) Comment
Date: Wednesday, November 21, 2018 11:47:33 PM

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Testimony:

I am Robert Acevedo, a member of Independence Care System (ICS) and the Civics League for DisABILITY Rights..

Most MLTC's focus more on the needs of senior citizens. I'm here to advocate for the disABLED community. Because only ICS understands the needs of people with physical disabilities, ICS has been the only managed long-term care (MLTC) plan in New York that regularly authorizes up to 12 and 24 hours of home care for people who need it. And now, as we all know from our year of advocacy on behalf of them, ICS is in danger of being closed because of the high-cost needs of its members.

Ideally, all MLTCs would be able to afford more home care hours for high-cost members if the state would only create a separate rate taking this high-needs population into consideration. This is a long-term problem that will only get worse as New York's population ages.

I am here to ask you to support this cause which is important to the well-being and diversity of NYC.

From: [REDACTED]
To: doh.sm.1115Waivers
Cc: [REDACTED]
Subject: 1115 Public Forum Comment
Date: Tuesday, November 27, 2018 2:34:11 PM
Attachments: [NOP Section 1115 Waiver Comments FINAL.pdf](#)

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Hi,

The Nassau-Queens Performing Provider System (NQP) is submitting the attached document as our public comments ahead of the Downstate Public Comment Day on Thursday. We appreciate the opportunity to provide feedback regarding the Section 1115 waiver and the DSRIP program. Please let us know if you have any questions regarding these comments. We are happy to be a resource in any way that we can.

Best,

Matt Hawley

Matthew Hawley

Policy Project Manager

Nassau Queens PPS

Office: [REDACTED]

Cell: [REDACTED]

www.nassauqueenspps.org



November 27, 2018

New York State Department of Health
Empire State Plaza
Albany, NY 12237

Re: Section 1115 Waiver Public Forum Comments

To Whom It May Concern,

Nassau Queens Performing Provider System (NQP) appreciates the opportunity to provide feedback to the Department of Health (DOH) regarding the Section 1115 waiver. This waiver was designed to use a managed care delivery system to provide benefits to New York Medicaid recipients, promote systematic efficiencies, and extend coverage to individuals who would lack health insurance otherwise. In the last few years, we have seen tremendous strides in increasing access, improving performance, and transitioning healthcare stakeholders towards value-based payments (VBP). NQP celebrates these successes. However, we have also provided some feedback and recommendations below to highlight opportunities for improvement.

As the fourth largest PPS in the state, we have primarily focused our comments on the Delivery System Reform Incentive Payment (DSRIP) program, though in some cases we have extended our comments more broadly to apply to any future programs that may catalyze delivery reform and the transition to value-based payments (VBP).

To contextualize our comments further, NQP has engaged our partners to ensure the transition towards population health and VBP continues even as the DSRIP program's end date approaches. Under NQP's current sustainability plan, each of NQP's three health system hubs –Catholic Health Services of Long Island (CHS), Long Island Jewish Medical Center (LIJ), and Nassau University Medical Center/NuHealth (NUMC)—will individually continue to ensure the health and well-being of its community members via a delivery system that focuses on community-based ambulatory care. The PPS will maintain an appropriate level of resources to support objectives and to prepare for an organizational ramp-down of the program. If DOH deploys a follow-up initiative to DSRIP, NQP will re-evaluate this sustainability strategy and weigh the potential opportunities of this new program.

The factors and context outlined above inform our comments below.

Empowerment of Community-Based Organizations

New York State is a nationwide pioneer in considering the social determinants of health such as food, housing, and transportation as critical components of healthcare. If an individual lacks stable housing or access to food or transportation, getting to medical appointments and taking medications may not be a priority to them. The healthcare system of the future will need to feature a collaboration of care between hospitals, primary care offices, behavioral health providers, and community-based organizations (CBOs).

CBOs are well-positioned to educate Medicaid beneficiaries about healthy lifestyle choices. They are trusted partners in their communities and can reach individuals in ways hospitals/health systems cannot. Policy and future Medicaid initiatives should empower them further to undertake programs and develop resources that can promote overall health and improve outcomes.

For example, earlier in the year NQP announced that it would be providing \$1.8 million to 33 CBOs in Nassau and Queens for health improvement initiatives and the development of health-related programs. These types of collaborations with CBOs hold tremendous potential to deliver person-centered solutions. However, it is worth noting that NQP faced many challenges working with CBOs as part of this initiative. In fact, only a fraction of the CBOs with which NQP partnered during Phase 1 of this initiative were equipped or capable of engaging in more robust partnerships as part of Phase 2. This may reflect some limitations for CBOs to fully engage in healthcare delivery going forward.

Enhanced Collaboration with Managed Care Organizations

Among other things, the DSRIP program seeks to catalyze the transition from fee-for-service arrangements to incentive-based models that emphasize prevention, promote value, and improve clinical outcomes. Arrangements between PPS network providers/partners and Managed Care Organizations (MCOs) are critical relationships during this transition.

While NQP has worked to educate the provider and CBO communities about VBP, barriers to MCO collaboration persist. There continue to be many comprehension gaps and misinformation, particularly in the provider community, around VBP and the overall shift towards incentive-based arrangements. Furthermore, some MCOs are hesitant to partner with CBOs. These hesitations may persist due to the enhanced oversight, support, and expense that partnerships between MCOs and CBOs would entail. In fact, many behavioral health CBOs lack the technology, staff, and processes to accept and exchange data with MCOs and other organizations involved in enhancing performance.

In future initiatives, DOH should provide clear guidelines from the beginning on how PPS should/can work with MCOs and should outline what MCOs are required to do. This could help facilitate more collaboration between MCOs and providers. Perhaps the state could even assume the role of liaison early on in the contracting process, offering monthly opportunities to gather feedback from providers and MCOs.

Additionally, MCOs, DOH, CMS, and various recognition programs measure and reimburse providers based on similar, yet ultimately different metrics. We would encourage the state to promote alignment between disparate programs in order to ease administrative burdens for the provider community, particularly when these metrics are tied to financial incentives.

Imperative for Regulatory Clarity

The healthcare landscape, particularly in New York, is under constant evolution. Changes in reimbursement models and technological innovations often outpace regulatory updates, leaving some regulations outdated. That is why we've been very pleased to see that DOH has undertaken the

Regulatory Modernization Initiative to update policies and regulations as needed to reflect a more modern healthcare environment. We continue to support DOH in this endeavor.

However, there are still areas in New York State's regulatory framework that either do not reflect the interconnectedness of modern healthcare relationships or lack sufficient clarity for all stakeholders to implement with confidence. One particular area our network providers have struggled with pertains to billing for integrated primary care-behavioral health services. The regulations surrounding this relationship have been very convoluted and complex for providers to understand, let alone for them to implement. Unless providers can be assured of their reimbursements, they will continue to be hesitant about participating in certain arrangements. We urge DOH to re-evaluate areas of healthcare regulations that may lack clarity and therefore unintentionally limit innovation or discourage person-centered care.

Potential of Information Technology

Information technology (IT) offers tremendous potential to shift how patients interact with providers, how patients take increased ownership of their own health, and how providers can collaborate more effectively with each other. Public policy should continue to reward and encourage innovations from the private sector that can improve outcomes, increase price transparency, and empower patients by avoiding overly burdensome or restrictive regulations on new technologies. During the regulatory process, DOH must not only consider the current healthcare and technology landscape but also the future healthcare ecosystem, which will be filled with technologies and IT infrastructure not yet created.

Unfortunately as part of the DSRIP program, NQP observed many barriers to adopting effective technological solutions. For example, NQP experienced many challenges working with Healthix due to their limited resources and inability to scale up quickly in attempting to create a health IT system that shares patient information with key clinical partners. In DSRIP Year 4, this remains an ongoing challenge. Regional health information organizations (RHIOs) must be assessed for scalability and sustainability before making them project requirements. This is a critical success factor for an integrated delivery system to work efficiently. In future initiatives, the state should work with RHIOs to ensure their effectiveness in sharing patient information across disparate providers.

Integration of Oral Health

DSRIP and similar state initiatives have encouraged the integration of previously disparate aspects of healthcare, such as primary care and behavioral health. However, there are still opportunities to ensure that providers improve coordination and collaboration to deliver optimal patient-centered care. One area that still demands further integration is oral health.

Dental care is often viewed as an optional component of healthcare, and as such affordability remains an issue. Medicare does not reimburse for dental services, Medicaid considers dental care as optional for adults, and employers are less likely to offer dental insurance than health insurance by a wide margin. However, optimal oral health is not simply a goal in itself, but is vital to creating healthier communities. Research has shown that tooth decay can result in an elevated risk for diabetes, heart disease, and stroke. The integration of oral health into overall health initiatives is critical to achieve



optimal overall health. Policy should increase access to preventive dental care visits, particularly for vulnerable, at-risk populations, like Medicaid beneficiaries.

Additionally, as far as innovative reimbursement or alternative payment models (APMs), dental care is often excluded. Restrictions frequently prohibit accountable care models in the dental world that align payers, providers, patients, health IT vendors, and community stakeholders to produce optimal healthcare and financial results. Policymakers should implement regulations that are flexible enough, and that expressly encourage dental professionals to participate in APMs, which will help to further medical-dental integration efforts as we move to more patient-centered healthcare systems. The state should consider including oral health as part of the array of services for coordinated care or adding dental to capitated care models.

We sincerely appreciate the opportunity to provide feedback on the Section 1115 Waiver, in particular the DSRIP program. We continue to support DOH's efforts to modernize the healthcare system and ensure New York remains a pioneer of innovation. We hope DOH will consider us a resource going forward on some of the topics outlined above.

Sincerely,

A handwritten signature in blue ink that reads 'Robert Hettenbach'. The signature is fluid and cursive, with the first name 'Robert' being more prominent than the last name 'Hettenbach'.

Robert Hettenbach
Executive Director
Nassau-Queens Performing Provider System

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From: DAN WINCHESTER [REDACTED]
Sent: Thursday, November 29, 2018 5:28 PM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum - Daniel J. Winchester Ph.D. Testimony on November 29, 2019
Attachments: NYSDOH Medicaid Redesign Team -1115 Waiver Testimony .docx

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Dear MRT Panel Members:

Attached to this communication is the written copy of the testimony I gave at the Institute of Medicine on November 29, 2018. I hope that my verbal remarks were understandable by all of you. Thank you very much for your understanding and I appreciate the time granted to me. Additionally, I have experience in objectivity assessing the effectiveness of a program and possess solid research skills. If you need any assistance in evaluating the merits of the 1115 Waiver demonstration project, please let me know accordingly. I noticed that you are preparing a project proposal(s) to CMs to apply the 1115 Waiver paradigm to specifically target the needs of children with disabilities and their families. I have extensive knowledge of that area both from personal experiences growing up with a disability and as an academic researcher. I can submit my resume to you upon request. My contact information is cited below the testimony itself.

Once again, thank you.

Sincerely yours,
Daniel J, Winchester, Ph.D.

NYS Department of Health Medicaid Redesign Team
1115 Waiver Testimony at the Institute of Medicine
Presenter: Daniel J. Winchester, Ph.D.
Date: 11/29/18

Members of the New York State Department of Health Medicaid Redesign Team, thank you very much for allowing me to enumerate why I feel that the Medicaid 1115 Waiver availability is of critical importance to the disability community of which I am part of. My name is Daniel J. Winchester. I am 66 years old and lead an active life. I was born with cerebral palsy which affects my hearing considerably enough to the point of near-deafness, speech to some degree, balance and coordination, in addition I also have a highly rare congenital heart condition called Ebstein's Anomaly, recently diagnosed which puts a limit on just how much I can exert myself physically. I cannot use my hands at all due to high spasticity. I utilize a head-controlled power wheelchair for my mobility needs. Due to my complex medical needs, I require continuous coverage of personal care hours given to my 5 assistants who work for me on a rotating basis under the split-shift framework with each working 12 hours. I'm a part of Independence Care System which thoroughly covers my multiple needs including wheelchair maintenance, repair and purchase and funds my fiscal intermediary homecare agency, Concepts of Independence, a Consumer Directed Personal Assistant Program that facilitates autonomous control of my life. The 1115 Medicaid Waiver would allow funds to be released so that the hours essential for my wellbeing as well as others with severe limitations and complex needs, including overnight shifts would be covered to the fullest extent possible. Anything short of that would actually compromise the quality of life that I and many others in similar circumstances currently enjoy. By the way, I have a doctorate in developmental psychology from Albert Einstein College of Medicine in case you were wondering. Thank you very much for your understanding and interest in assessing the merits of implementing the 1115 Waiver.

Daniel J. Winchester, Ph.D.



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From: Blech, Miriam (Mashi) [REDACTED]
Sent: Thursday, November 29, 2018 5:01 PM
To: doh.sm.1115Waivers
Subject: ArchCare's public comments from today's NYS DSRIP PAOP and Downstate MRT Public Comment Day
Attachments: DOH Public Hearing re DSRIP Funding.docx

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Mashi Blech
Director of ArchCare TimeBank



Miriam Blech
Director
33 Irving Place, 11th Floor, New York, NY
10003



Visit us on the web at www.archcare.org or call to speak with one of our Care Navigators at (855) 951-CARE, seven days a week.

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New York State DSRIP PAOP & Downstate MRT Public Comment Day

November 29, 2018

ArchCare Parish and Interfaith Outreach and TimeBank

Michael Guglielmo and Mashi Blech

My name is Michael Guglielmo and I am the Director of Parish and Interfaith Outreach for ArchCare, the healthcare ministry for the Roman Catholic Archdiocese of New York. I am very pleased to be here with to champion our efforts on Staten Island under the auspices of the Staten Island PPS.

ArchCare's work with the Staten Island PPS has a two pronged approach, promotion of health literacy and launching the TimeBank, a reciprocal volunteer exchange. Both serve to improve overall population health on the Island.

In terms of health literacy, the biggest impact we have had on Staten Island is making connections and building networks. We partner with community based organizations, and interfaith communities throughout Richmond County. We have provided health education to individuals in the community on topics as varied as blood pressure control to diabetes prevention to healthy aging; among many others. This is just one way we support healthier lifestyles, all while increasing participant understanding of Health Literacy. Through our health literacy outreach, we have encountered over 11,000 Staten Islanders.

We also leverage our Health Literacy programs to encourage participants to make sure they either have health insurance or, if covered, utilize it properly, helping to reduce ED's as a point of primary care. This helps the PPS insure SI residents have a PC or health home. So, if we offer flu shots we also make sure community members know to connect with their provider or enroll, if needed.

In addition to the wonderful collaboration in Staten Island with the PPS, ArchCare has also invested a great deal of effort throughout the city with other DSRIP partners. One example is the recognition we received at a DSRIP City-Wide Project Advisory Committee Meeting where ArchCare was complimented for excellent patient care management services provided to the OneCity Health PPS related to the Care Transitions Program at Harlem Hospital.

ArchCare believes in a personalized approach to healthcare and one of the best ways we achieve this is through our TimeBank program where individual needs are met and social isolation is addressed. I am happy to introduce Mashi Blech, TimeBank Director to tell you more about the TimeBank's impact on the Staten Island and other NYC communities.

Good afternoon. I am Mashi Blech and I am delighted to be here.

TimeBanks are networks of individuals providing key assistance with concrete services, including instrumental activities of daily living, as well as essential emotional and social support. Members of the TimeBank give whatever they can and request what they need. It's a reciprocal exchange system where members earn an hour for every hour provided. No money exchanges hands, only time. Currently, the ArchCare TimeBank has close to 2,000 individual members and 113 organizational members; 62% of our members are over the age of 60 and most have very low incomes. Half of our members do not speak English. Almost 80,000 hours of exchange have been recorded since the ArchCare TimeBank launched in 2014.

Through DSRIP, TimeBank has focused on filling gaps in formal services and addressing loneliness, a public health epidemic and a critical social determinant of health. Escorts to the doctor, shopping assistance, errands, cooking, post hospitalization support are just a few of the services TimeBank members provide. With the enthusiastic support of the SI PPS, the ArchCare TimeBank launched and now operates a vibrant TimeBank network.

Key support from Bx Partners for Healthy Communities has allowed TimeBank to more than double its Bx membership and receive training on outcome measurement. TimeBank is also working with NYU Brooklyn's PPS.

With families dispersed, with an aging population and with shrinking resources, we all know how critical it is to identify innovative strategies to support those at risk. Individuals can join the ArchCare TimeBank today and have almost 2,000 people on their team.

Social workers and nurses from our MLTC and PACE are now referring individuals at risk who are lonely and TimeBank matches them for weekly calls and sometimes visits based on interests, language and in some cases geography. We are in the process of collecting pre and post data measuring loneliness and distress. Retrospectively, nearly 100% of these individuals who were engaged for 6 months with the TimeBank report that they benefited: 77% say their mental health improved and 44% report their physical health improved. 79% report the TimeBank helps them feel less alone.

We are very grateful for all the support the ArchCare TimeBank has received and hope to have the opportunity to continue to work with the PPSs to expand, innovate and improve health outcomes, one hour at a time.

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From: Joan Clark [REDACTED]
Sent: Saturday, December 1, 2018 2:41 PM
To: doh.sm.1115Waivers
Cc: Joan Clark
Subject: 1115 Public Forum Comment -Healthix

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To whom it concerns,

On behalf of Healthix, one of eight Qualified Entities in New York State, I am pleased to provide comments to the NYSDOH public health day for New York's 1115 waiver program, held November 29, 2018.

The 1115 MRT waiver and the DSRIP program has significantly improved access to quality care for Medicaid beneficiaries, increased patient care coordination and continuity of care as well as positively impacted care provider collaborations.

Healthix participates in 9 PPSs in our market place. Our participation in these PPSs has allowed us to witness the substantial progress and success the PPSs have achieved to improve patient care and quality, as well as curtail health care expenses and costs that can be avoided. PPSs have also fostered true collaboration between and among care providers (including hospitals, skilled nursing facilities, home care agencies and behavioral health providers). These community based providers (CBOs) are essential care providers and many of the PPSs have focused on improving collaborations with these entities. In particular, the Staten Island PPS has achieved significant success in creating partnerships with CBOs that will result in long term sustainability for residents. Healthix is also working with the Mount Sinai PPS in a research study regarding the role of CBOs in decreasing length of stay and readmissions in Medicaid recipients.

Healthix supports the continued efforts of the State regarding the 1115 Waiver and is grateful to be part of the consortium of health care providers who are working to improve care for all Medicaid beneficiaries and all New Yorkers.

Many thanks,
Joan Clark

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From: Mary Han [REDACTED]
Sent: Friday, November 30, 2018 3:35 PM
To: doh.sm.1115Waivers
Cc: Joseph Conte
Subject: 1115 Public Forum Comment
Attachments: 20181129_SI_PPS_PAOP.pdf

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Good afternoon,

Staten Island Performing Provider System would like to submit the attached written public comments for the DSRIP Project Approval and Oversight Panel.

Regards,
Mary Han
Director of Continuing Care and Quality Management
Staten Island Performing Provider System
1 Edgewater Plaza, Suite 700
Staten Island, NY 10305
[REDACTED]

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Project Approval and Oversight Panel November 2018

Introduction

Staten Island Performing Provider System (SI PPS) has engaged 95,000 unique Medicaid patients to-date through our 75 partners and their respective clinically integrated medical, behavioral health, and social service programs. Intensive care management and health home at-risk programs ensure patient needs are met through on the ground care coordination and direct referrals to PPS programs. Partners have access to frequently distributed patient outcomes and gaps in care reports to assist with targeted outreach to individuals at-risk of potentially preventable complications, emergency department (ED) visits, and hospitalizations. These reports are populated with patient-level data from various sources. Bidirectional data sharing with hospitals, Healthix, and managed care organizations (MCOs) refines medical, behavioral, and social determinants of health (SDOH) data stored in the SI PPS electronic data warehouse to improve ongoing population health reporting.

Transformational workforce efforts funded by SI PPS have created scholarship opportunities and jobs for community health workers, certified peer recovery advocates, health coaches, mental health clinicians, and certified nursing assistants among SI PPS partners and public-sector agencies. Cultural competency and health literacy training for partner staff positively impacts patient survey outcomes and performance measures while building trust between patients and providers. Collaboration with public sector and local governmental agencies ensures coordination, data sharing, and input from criminal justice, education, and consumer advocacy organizations. SI PPS representation on community facing coalitions, task forces, and workgroups informs public health policy, regulatory actions, and cross sector public health and safety programs.

Accomplishments since 2015:

- 62% reduction in Potentially Preventable ED Visits (PPV)
- 57% reduction in Potentially Preventable Readmissions (PPR)
- 60% reduction in PPV for members with behavioral health diagnosis
- 32% increase in follow-up care after hospitalization for mental illness
- 66% reduction in admissions due to diabetes related short-term complications (PQI 1)

Technology

In August 2018, SI PPS and the Office of Alcoholism and Substance Abuse Services (OASAS) signed the Universal Consent form that complies with Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2, therefore allows OASAS providers to share a

client's substance use disorder treatment history with other health care providers and it also allows other health care providers to share patient treatment history with the OASAS providers.

In collaboration with HEALTHIX, SI PPS can advance data sharing using our platform and technology for seamless electronic exchange of information. This facilitates the creation of comprehensive integrated treatment plans to support the individuals who need help most.

Social Determinants of Health

Staten Island PPS has made significant contributions to strengthen provider relationships with community-based organizations (CBOs) who provide a social determinant of health service to our patients. Particularly, we address housing, food security, health literacy, social isolation, and employment. We partner with 19 CBOs on a variety of projects. To-date, we have paid out over \$6,000,000 and are projected to double that (\$12,000,000) by 2020.

We'd like to highlight the Healthy Neighborhood project, which partnered with the three local colleges for Phase I and has now partnered with two CBOs in the North Shore, awarding each \$50,000 in grant funding, to organize the community and work on projects to impact local health disparities with a focus on diabetes education and prevention, nutrition and childhood wellness.

We have also engaged Staten Islander's experiencing social isolation in the Timebank reciprocal volunteer exchange program and have partnered with 209 unique faith-based groups to bring health literacy education programs reaching approximately 12,000 individuals since 2017. SI PPS was contracted by the New York Public Library (NYPL) system to provide all health literacy programming for branch locations across Staten Island and have coordinated 25 workshops at 12 different Staten Island NYPL locations.

Through our partnership with City Harvest, Staten Island PPS has been able to address food insecurities in multiple ways including our Rx for Food program where residents get a prescription for free produce written by a healthcare provider. Patients are able to collect food at mobile market sites twice a month. We have also supported partners who have set up satellite mobile market sites for their clinic's patients. Our PPS has also adopted a 'Community School' and launched a successful 7-week "Train the Teacher" program using City Harvest Cooking Matters curriculum in every 5th grade class.

Staten Island PPS partnered with local CBOs (including the Pride Center of Staten Island, Disability Ally Initiative, Intersections for Military Cultural Awareness, Community Resource Exchange for Building Equitable Health Care Organizations and Tannenbaum for Inter-religious Awareness) to deliver workforce development training under the Cultural Competency and Health Literacy workstream, providing thousands of hours of training to over 8,000 SI PPS partner employees.

In July 2018, SI PPS launched the Bridge Home pilot in partnership with the New York City Department of Homeless Services/Department of Social Services and St. Joseph's Medical Center Residential Services team to engage and re-house individuals residing in NYC shelters. A data sharing agreement between SI PPS and Department of Social Services allows both parties to share a roster of mutual clients. The St. Joseph's outreach team receives the list of mutual clients

and engages with them in the shelters to assist with voucher paperwork, apartment viewings, rental applications, landlord interviews, coordination with moving and connection to Home Base after care. Thus far, families have been successfully re-housed from the shelter system, with over 10 more families on the path to permanent housing.

Staten Island PPS is working with New York City Department of Health and Mental Hygiene (DOHMH) on a pilot to improve access to health care services and resources for (New York City Housing Authority) NYCHA residents within NYCHA buildings and Cornerstone Centers. Hot spotting for chronic conditions has identified four high-risk neighborhoods targeted for intervention. The Staten Island PPS is working with partners to host trainings, workshops, and classes within the NYCHA Cornerstone buildings overseen by local CBOs. We have also collaborated with NYCHA and the College of Staten Island to recruit six residents for a free Community Health Worker certificate program. Community Health Workers (CHWs) will be placed in jobs with CBOs, with SI PPS supporting the salary for up to three months, where they will use new skills to offer residents and peers health coaching and navigation to health care services on Staten Island.

Workforce

Staten Island PPS has provided more than 35,000 hours of new training to more than 12,400 partner employees at a cost exceeding \$14 million dollars to-date. More than 50 partners continue to access this training, often being a resource not available to many small organizations prior to (Delivery System Reform Incentive Payment) DSRIP. The success of this model is a new partnership between 1199SEIU Training and Employment Funds (TEF), our partner organizations, higher education represented by the College of Staten Island (CSI), and SI PPS as the catalyst and manager of innovative programs. Beyond training, a scholarship program between SI PPS and CSI has served more than 80 students studying Mental Health Counseling or Social Work providing our partners with both interns and new hires. Our new CHW program (the third cohort of CHW) with NYCHA and CSI is another example of anticipating and meeting the needs of the community on an ongoing basis.

Another first for the PPS and New York state is the design and implementation of a Federally Recognized Registered Apprenticeship program for Certified Nursing Assistants. This program is designed to increase the hiring pipelines, reduce overtime and staff turnover, and improve employee morale. In addition, we envision developing Apprenticeship programs for CHWs, Home Health Aides, Peer Counselors and Data Analysts. The funding for such programs can come from Federal, State, and non-governmental sources.

Apprenticeship learning can be implemented in high schools, for the unemployed, and those seeking a career ladder within health care. According to a Center for American Progress report released in 2016, “States, often regarded as so-called laboratories of democracy for their ability to experiment with innovative policies, have been leading the way in developing strategies to prepare more workers for employment through apprenticeship”.

Addressing Opioid Epidemic/Substance Use and Mental Health Disorders

Staten Island PPS has provided comprehensive support and strengthened collaborations among substance use disorder and mental health treatment providers, community-based organizations, and state/local government units to address the opioid epidemic and improve behavioral health wellness on Staten Island. Through collaborative efforts, improved workflows, expanded provider capacities, and innovative programs in treatment centers, emergency departments, criminal justice, and other settings, there has been significant outcome improvements including a 58% reduction in preventable ED visits for people with behavioral health diagnoses, 32% increase in follow-up care after hospitalization for mental illness, 9% increase in antidepressant medication management, and 19% increase in engagement in substance use disorder treatment. Over 2,000 Medicaid individuals have received medication assisted treatment (MAT) and support services for opioid, alcohol, and other substance use disorders. A 52% reduction in their ED utilization was observed for these individuals.

In January 2017, Richmond County District Attorney Michael E. McMahon and local collaborating partners initiated a unique initiative, the Heroin Overdose Prevention and Education, or HOPE Program. The program aims to redirect those charged with low-level drug possession, post-arrest and pre-arraignment, away from the criminal justice system and toward community-based health services. While at the precinct, those arrested are met by a peer mentor and are given a naloxone training, and should they choose to participate in HOPE, linked to a 24/7 Resource and Recovery Center where they are assessed by a behavioral health clinician. 24/7 operation of Staten Island Resource and Recovery Centers and training to certify peer recovery coaches was supported by the Staten Island PPS. By meaningfully engaging with treatment providers over the following 30 days, HOPE participants are given the opportunity to engage in life-saving treatment and avoid a criminal record. Since its inception, nearly 500 individuals have benefitted from the program, a success rate of 95%.

In November 2016, SI PPS in collaboration with Staten Island Partnership for Community Wellness and Richmond University Medical Center (RUMC) implemented the ED Warm Handoff program to reduce avoidable SUD-related ED visits with peer support and expedited linkages to SUD providers. There were 1049 engagements in the first year of implementation and a 27% reduction in preventable ED visits for people with a substance use disorder and other behavioral health diagnoses. The acceptance and linkage rate for engaged individuals was 15% higher compared to the Substance Abuse and Mental Health Services Administration (SAMHSA) reported national average.

A Buprenorphine Detailing campaign was conducted to support Staten Island waived Bupe clinicians in addressing opioid use disorder by providing Medication-Assisted Treatment (MAT) and 66% of the 65 buprenorphine waiver providers were engaged. Training and technical assistance have been offered to increase the number of waived providers by 50.

Staten Island PPS partnered with the Office of the Staten Island Borough President to fund an innovative program to pilot an addiction treatment platform called A-CHESS. The A-CHESS program is a recovery support and relapse prevention tool that has shown to improve treatment adherence. Features include counselor check-ins, surveys and questionnaires, journaling, virtual support groups and messaging, and high-risk location alerts. We worked with CHESS Health to

implement a smartphone application with four substance use disorder treatment providers over the summer of 2018. Bridge Back to Life, Christopher's Reason, Silver Lake Behavioral Health, and YMCA Counseling Service have integrated the app and clinician dashboard within their treatment programs. There have been over 190 clients that have enrolled in the application to-date and all four providers are tracking daily check-ins, survey completions, client messages, and logins within their organizational dashboards.

In July 2018, a 911 diversion program was launched on Staten Island to redirect 911 callers with low risk mental health concerns through a revised triage algorithm to NYC Well for assessment by a counselor and further connection to Staten Island's 24/7 call center, SI CONNECT, for transportation, and direct appointment scheduling. Collaborating partners include NYPD, FDNY, City Hall, NYC DOHMH, and Vibrant Emotional Health. The program aims to improve care for low acuity behavioral health clients, reduce the burden of inappropriate EMS and ER utilization and promote the use of behavioral health resources and services in the community.

Primary Care and Integrated Care

Staten Island PPS has fully engaged nine primary care practice sites working on various projects and have 14 other practices (plus four more pending approval) involved in our Population Health Improvement Project (PHIP). All nine primary care practice sites and nine of the 14 PHIP partners have integrated behavioral health specialists to deliver mental health and substance use disorder screenings and services to improve health outcomes either through their internal Behavioral Health employees or through the Mental Health Service Corps graduate social worker.

The nine primary care practice sites and six PHIP partners have achieved Patient-Centered Medical Home (PCMH) level 3 recognition with our PPS supporting their systems transformation. We financed the technical assistance provided to these practices by HANYS and are currently working to connect partners with a Technical Assistance (TA) vendor funded by NYSDOH for NYS PCMH recognition. There are four practices in the process of connecting with NYC REACH. Across primary care and behavioral health settings, over 27,000 individuals have received integrated behavioral health and primary care services since April 2015.

Care Management

Through its SI CARES and HEALTHi programs, SI PPS has expanded care coordination services which are foundational and essential to supporting high-risk individuals to close gaps in care and address social service needs, and to improving population health outcomes.

Staten Island Community At-Risk Engagement Services (SI CARES) is the Health Home at-risk program, a care coordination program that manages moderate-risk individuals whom are ineligible for the NYS Health Home program by providing a dedicated care manager and access to high quality healthcare and social support services. Over 8,700 individuals have received services and we have seen an 8% reduction in their ED utilization.

HEALTHi (Helping, Engaging, and Linking to Health interventions) is an intensive care management program that utilizes an interdisciplinary *on the ground* team approach to provide a safety net of resources to individuals with complex chronic conditions who are also affected by

social determinants of health. Since April 2018, only 20% of engaged individuals have had an ED visit, 96% completed primary care/preventative care visits, and 100% had a follow-up visit after hospitalization for mental health and substance use illnesses.

Continuing Care

DSRIP has established sharing of best practices and improved outcomes for skilled nursing facilities and home care agencies. We have achieved successful implementation of INTERACT in 10 skilled nursing facilities and four home care agencies. A sepsis protocol has been implemented at 10 skilled nursing facilities with 156 nurses newly IV certified and 54 nurses newly trained in phlebotomy since January 2018. Palliative care has been implemented at 10 skilled nursing facilities with a total of 8,950 continuing education units awarded across 1,039 classes over 2016 and 2017.

Additionally, in March 2016, Staten Island PPS implemented telemedicine service in three residences of Office for People with Developmental Disabilities providing weekend coverage from 7 PM Friday to 6 AM Monday. As a result, Cerebral Palsy Associations of New York State (CPOFNYS) successfully received a grant from the Dormitory Authority of the State of New York (DASNY) to fund the expansion of this telemedicine service to all its residences in the New York City region. CPOFNYS is implementing telemedicine at 105 locations in all five boroughs in 2018. The Department of Health's reported statistics below show the importance of improving care for persons with Intellectual/Developmental Disabilities (I/DD):

- An estimated 1 in 21 hospitalizations in NYS involve persons with I/DD
- 1% of I/DD population uses in-patient settings, yet 25% of total Medicaid expenditures for Mental Health services were on in-patient care
- While total cost of care for the nearly 97,000 individuals analyzed within the I/DD system is \$7.7B, Acute/Primary Care services account for only \$1.1B of these services

Managed Care Organization Engagement and Value Based Purchasing

Staten Island PPS has fully engaged with the leadership of five Managed Care Organizations: Emblemhealth, Fidelis, Healthfirst, HealthPlus and UnitedHealthcare. We have been working synergistically in population health management on key conditions affecting the community including asthma and diabetes. By being early adopters of bi-directional data exchange with MCOs, we have been able to improve the quality and detail of information for providers which helps us prioritize timely interventions. Collaboration will help shift towards value-based payment for Medicaid to help achieve greater than 80-90% of total MCO-PPS payments.

Conclusion

Transformation, innovation, and collaboration among all domains has resulted in a 62% reduction in preventable ED visits, surpassing DSRIP goals. High performance and quality improvements drive additional funding and enhance the business case for the SI PPS transition to a future state model for managing value based payment (VBP) arrangements post-DSRIP.

doh.sm.1115Waivers

From: Pez Ben [REDACTED]
Sent: Friday, November 30, 2018 3:14 PM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment

ATTENTION: This email came from an external source. Do not open attachments or click on links from unknown senders or unexpected emails.

Hello.

My name is Philip Bennett, a consumer-directed home care worker and person with a disability.

I'd like to add to the in-person comment I delivered yesterday, November 29th, 2018, at the School of Medicine in Manhattan, 1216 5th Ave.

Cutting funds for long-term managed care agencies such as Independence Care Systems reduces the ability of people with disabilities to pursue happiness and for workers such as I to do our job in a truly fulfilling manner.

Another factor driving workers away, along with the low pay, made lower by the change in overtime regulations, is the electronic visit verification (EVV) regulation which, if it goes into effect, will likely force workers and consumers to submit private information to consumer-directed agencies. Workers should not be required to carry a device which allows "big brother" to monitor their movements. It was wrong in South Africa during apartheid with the passbooks and it's wrong in the United States today.

These regulations, which are costly to the taxpayers to set up and maintain, make it harder for consumers to locate and hire qualified workers and will force more of them into expensive and undesirable institutions.

I hope the NYS Board of Health will do all in its power to resist the EVV regulation which, hopefully, will be repealed before it can take effect.

Sent from [Mail](#) for Windows 10

doh.sm.1115Waivers

From: Amber [REDACTED]
Sent: Monday, December 3, 2018 3:47 PM
To: doh.sm.1115Waivers
Subject: CCO/HH survey please add to public comment
Attachments: attachment 1.pdf

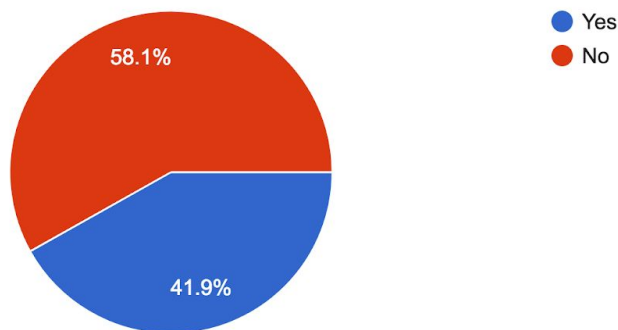
CCO/HH Participant Survey

This survey has been developed by OPWDD Family Advocates for purposes of trouble shooting any issues or concerns with the recent changes implemented in NYS on July 1, 2018. All MSCs Medicaid Service Coordinators were discontinued. Individuals with MSCs were told that they must join a CCO (Care Coordination Organization). CCOs offer two options either HCBS Basic care management or A Health Home Care Manager, We would like to continue to make our voices heard. We intend to share the results of this survey so that improvements can be made.

Survey Open From October 10th-December 3rd 2018

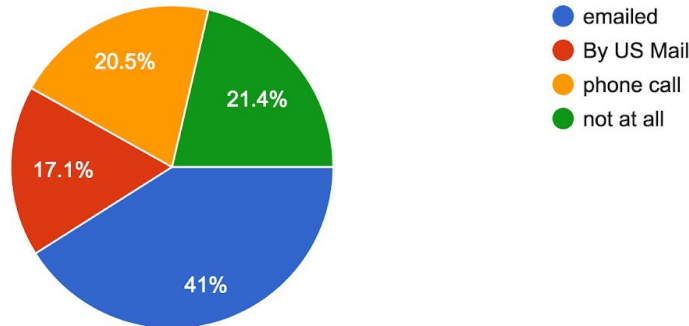
Did you understand the Care Coordination Organization /Health Home program rollout before it happened?

129 responses



How were you informed?

117 responses



What were you told?

98 responses

1. Not enough
2. just that the transition was happening, but not what it entailed
3. nothing other than the date it was taking place
4. I received the printed materials prepared by OPWDD, but help from SKIP our MDC provider was very poor
5. I was sent a flyer explaining the change over to CCO's
6. Changes made in OPWDD organization, less visits or help if I chose "Basic" over comprehensive".
7. I actually read the application and sent comments which were ignored by OPWDD.
8. need to choose basic or comprehensive by next week or won't get benefits
9. We were given info at least six months or even longer about what was taking place
10. MSc is not going to exist and
11. Attended information sessions on it through OPWDD before the turnover. I was told we'd be able to keep our MSC (hopefully) but they were just going to switch to another organization. This was to reduce the conflict of interest from services.
12. That it was happening by July 1st
13. Comprehensive description of what was coming
14. mscs were becoming care coordinators
15. That some changes were gonna be made but in the end everything was gonna stay the same
16. I don't remember any of it!

17. Since you have self direction you should choose Home health comprehensive since you would not get enough support with basic
18. A new system being rolled out.
19. Services are being centralized under CCOs to prepare for managed care
20. By my coordinator
21. Replacing MSC system. To be conflict free. More oversight on health issues.
22. M*****
23. Changing to new Care Coordination model and that my current Medicaid Service Coordinator would help with the transition
24. That the change would happen but that details would be forthcoming--that nobody knew anything, not even the supervisors knew specifics or who would be our contact people, which appears to have all been true (i.e. the the start up was a mess and nobody was told specifics).
25. I was told that my MSC would now become a Care Coordinator for Life Plan
26. I found out from GROW, the parent advocacy organization.
27. that opwdd was changing something which does nothing but make my life more difficult.
28. My msc did very little. NYS as far as I can remember sent nothing via mail or email.
29. My daughters MSC would become her Care Coordinator under a new organization. She would be the point person on all services. The roll out would be done in phases.
30. There were changes being made and instead of having msc's we wouldn't be dealing with the agency only the healthcare agency in which you will have a care coordinator
31. attended several seminars provided by DDSO and the CCOs. I was told that MSC would no longer be a service and that a similar but enhanced service would be provided by a CCo.
32. That we needed to make a change. Very little explanation
33. Not much as the MSC did not have a lot of information
34. email from skip of ny
35. "It's all changing and it's going to be a mess"
36. Whatever information OPWDD put "out there" for public consumption
37. conversation with MSC
38. That the new system would incorporate both Medical Home and Service Coordination
39. That we'd be moving toward a " more coordinated system of care"
40. was fpgiveninfo about the I/DD health home and care coordination
41. that changes were coming
42. That current MSC would explain further details
43. That MSC's would become Care Managers under the CCO's
44. I read all the stakeholder info on line i went to 3 question and answer sessions at OPWDD, FREE and QSAC
 now services would be CONFLICT FREE because the MSC/ CARE COORDIATOR would not be affiliated with an agency
 Care coordinator would be so much better than MSC
 My care coordinator is my former MSC her office is in QSAC. I heard a lot of lies about how much better things would be. I heard nothing about managed care

45. Was also informed by multiple public meetings and OPWDD policy documents. The essence was: Conflict-free Case management is coming, as the first step in a multi-year transition to Managed Care
46. It was out of My son's current(at the time) agency's control. That they were very unhappy about the change. That we needed to choose the complex/comprehensive option in order to keep the same coordinator or to have our SD work -as the basic option would not give us access to coordination service without very long wait times- months and that that would be a problem with our SD launch- felt very confusing and coercive- we were/are worried!
47. we are changing who we are working for- nothing is changing
48. That the MSC will become your Care Manager.
49. I didn't understand the changes
50. That I needed to sign some paperwork for the change to a new system but not to worry because nothing is changing. Which we all know now isn't true.
51. I was told that it would be better for me. I am not sure and what is tier 4 and why do I suddenly qualify
52. That there would be no more MSC"s and they would be replaced with care coordination which would have "life plans."
53. that managed care would be for all special needs people who receive medicaid/medicare service
54. I sought out meetings. Our Broker was essential - her help and advice was crucial
55. That the program would now include coordinating medical care.
56. We title now more MSC
57. nothing
58. That it would be full coordination if services
59. There will be a change.
60. I took the Webinar. I heard it and understood it, but that is not the reality of it and there are a lot of missing pieces.
61. Our MSC services were moving over into Care Management effective July 1, 2018 and the agency would be changing to a Care Management agency in which the Care Manager would now be reporting to.
62. Not a whole lot other than MSC's were being eliminated and CCO was taking over.
63. Basic info. Few if any details that could be confirmed.
64. I was told which one my current msc was going to be in.
65. Discussion with my MSC but he did not know very much in June
66. That we could keep our MSC who would be moving to a CCO organization
67. clarify question above-- we were informed by MANY sources: emails from OPWDD, from our MSC organization, from SANYS to name a few. There was LOTS of forums by our existing MSC agency (LIAC), OPWDD and the CCOs. We were "reassured" that this was NOT managed care, it would be "better" and that there would be few negative changes and people would transition with their MSC. Many of the power points, especially those by OPWDD were canned, and the OPWDD reps were stating party line...and often with vague or over-reassuring information. It was also clear, and stated, that there were (too) many still unanswered questions and unclear expectations. Neither OPWDD or the CCOs knew what would be happening before the deadlines: the process

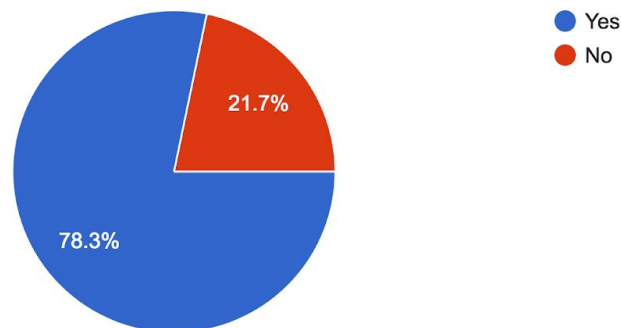
was not planned out, was rushed, and was evolving moment to moment. Both CCO and OPWDD reps stated that although they requested extensions so this would not have to roll out in June, CMS refused to allow an extension.

68. It was really for those who are not being cared for by their parents. and that I wouldn't really notice any changes.
69. medicaid coordinator during May 2018 bi- annual review advised that there was an upcoming change and handed me a colored flyer. i was then told that if i wanted to continue services i would have to sign a form and if i didnt agree to the more involoved "management" i would barely receive any assistance.
70. medicaid service coordinators would now be care coordinators
71. New change msc now cco
72. That a change was happening
73. That no one was sure of details
74. a new system was replacing MSC
75. I went to 2 forums about Jay Nagy's CCO and one run by OPWDD. I was told it was preferable to sign my son up for a Health Home Care Coordination because it was a more "robust" service. Since then, I have discovered that there is no plan in place to accommodate individuals who have private health insurance in the Home Health option. Based on what I know now, I think I probably should have signed my son up for HCBS Basic Care Management to handle his OPWDD approved services only.
76. I signed up for an information session presented by OPWDD which I learned about from an email from Parent to parent of Long island. The shift to "person centered" planning was explained as well as the change in structure to Care Coordination vs. Medicaid Service Coordination. It was very poorly explained to me by the MSC I had at the time, who then quit the agency and my son's case fell through the cracks.
77. What I learned I learned mostly from parents
78. When I asked our MSC, when I heard from other parents
79. I do not rembmer - but I was asked to sign the comprehensive plan, and when I said no, they were persistent.
80. Nothing much except it would be u Dee one umbrella
81. That it would be the same as before, but my MSC would now be called a Care Manager. I have no idea what CCO can offer me. All I know is hearsay from others. I am on my 3rd care manager since 7/1/18 (Head Injury) and none of the supervisors call back or respond to emails.
82. That it would be a better organized system. So far it is more bureaucratic, more costly to tax payers, and not improved at all for people just entering Self Direction.
83. The OPW would be forming Care coordination organizations that would replace the current system because they are trying to also coordinate health care eventually leading to Managed Care.
84. Only that the name would change.
85. As we have gone along I have gotten more information every time I have met with my care coordinator

- 86. I needed to come to the office to sign documents for care coordination and was discouraged from selecting basic and wound up getting home health care
- 87. Not sure
- 88. Our mcs
- 89. Former MSC told me, but not explanation
- 90. Not much was clear. Most good info came from special needs lists
- 91. Attended information meetings
- 92. Being moved to a different program
- 93. That the MSCs would be changed to CCOs.
- 94. in person told that an IAm assessment (no description offered) had to be done and would take hours of in-person interview
- 95. Not much just that may MSC would be transferring to care design ny but it was clear she was not given much information.
- 96. A lot of confusing information
- 97. My care coordinator
- 98. we no longer would have a medicaid service coordinator and we now should sign up with a new organization that provides care coordination. Same thing but different organization.

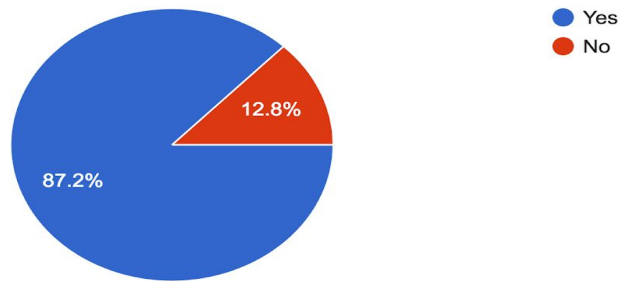
If your primary language is not English, were you given adequate information in your primary language?

46 responses



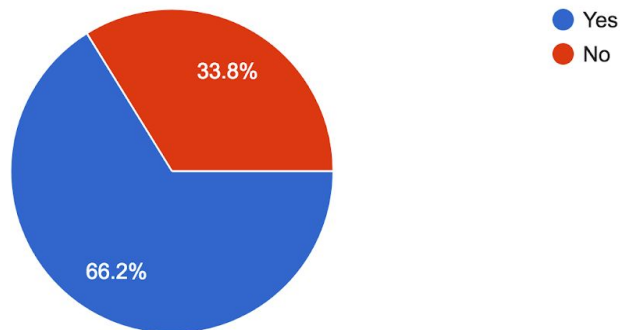
Have you been provided information about your care manager in a language you understand?

109 responses

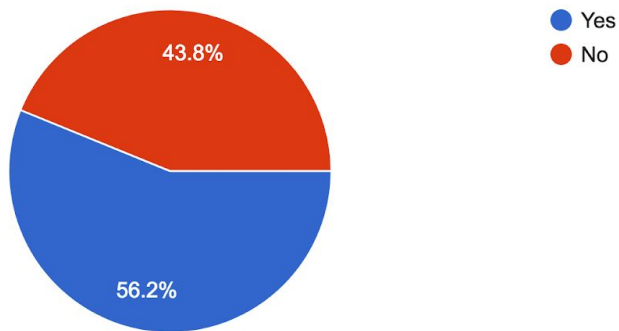


Have you ever been told anything about the Individualized Service Plan (ISP) being converted to a Life Plan (LP) from your Medicaid Service Coordinator or Care Manager ?

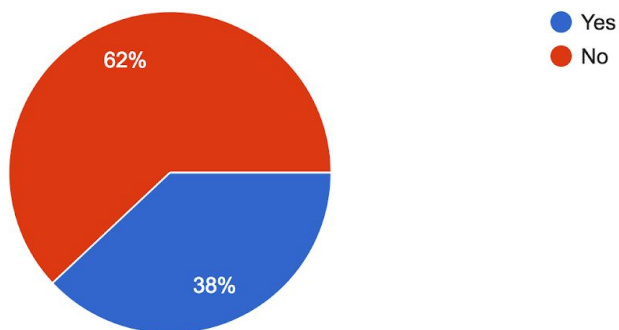
130 responses



Are you aware that the ISP will be converted to a life plan by July 2019? 130 responses

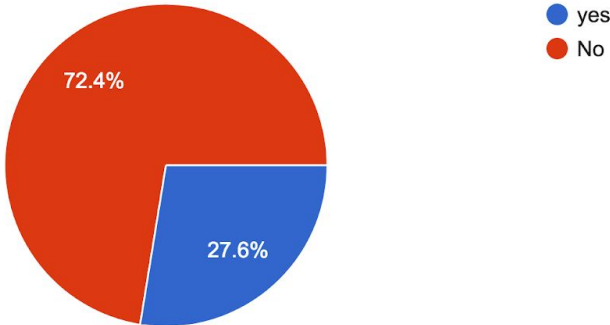


Have you ever been told anything about the "I Am assessment" from OPWDD or your CCO/HH? 129 response



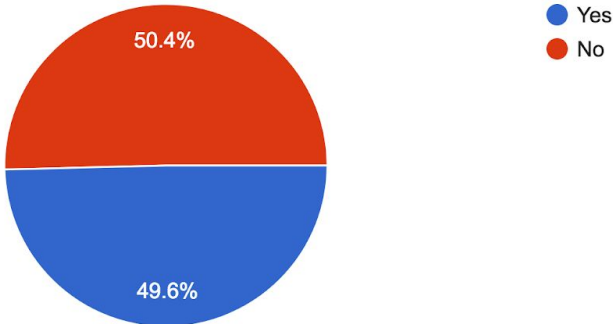
Did your MSC or Care Manager explain to you how you or your child's confidential information will be handled by the new CCO and how they will protect you or your child's privacy rights?

127 responses



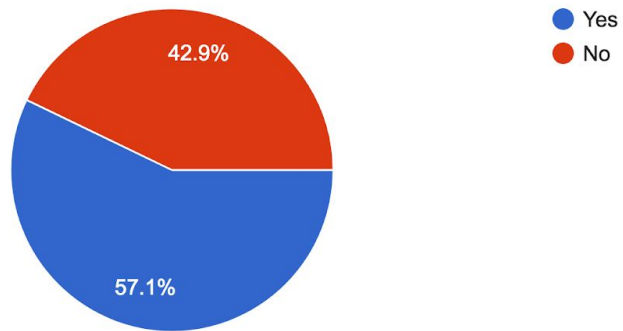
Do you have a written notice with the name of your care manager?

127 responses



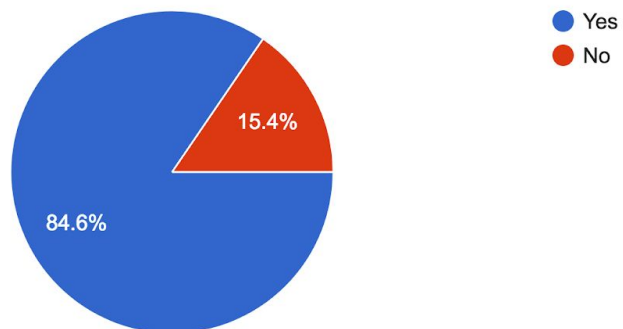
Do you know what number to call to get help?

126 responses



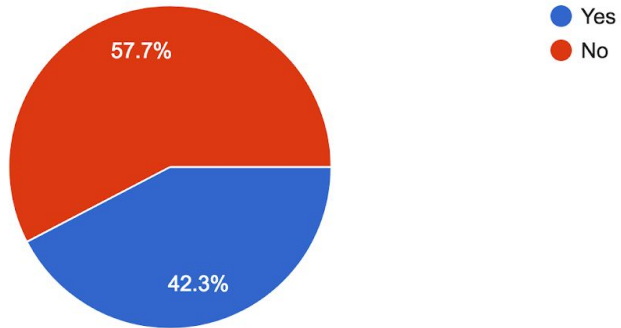
Are you enrolled in a Care Coordination Organization/ Health Home ?

123 responses



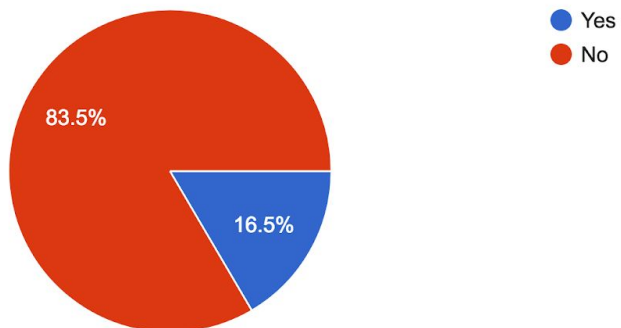
Are you enrolled in Basic HCBS Plan Support?

111 responses



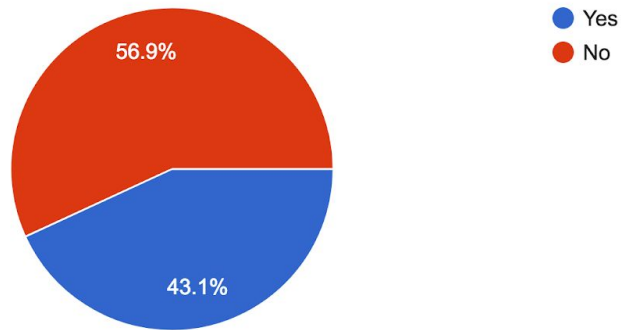
Have you completed the I AM assessment?

127 responses



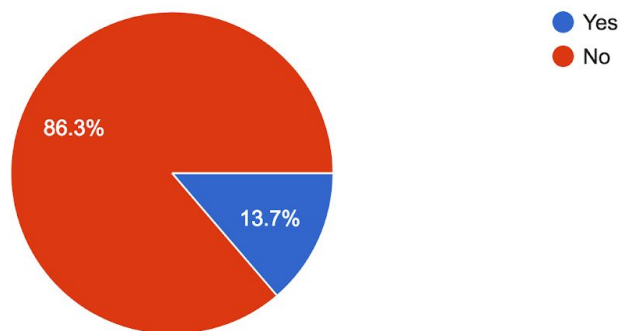
Were there any technological difficulties doing the I AM?

51 responses



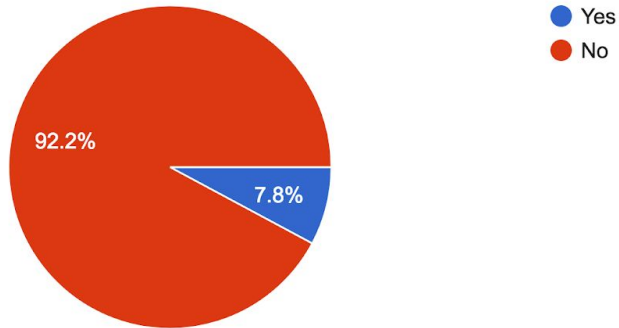
Has the Care Manager developed a Life Plan with you yet ?

124 responses



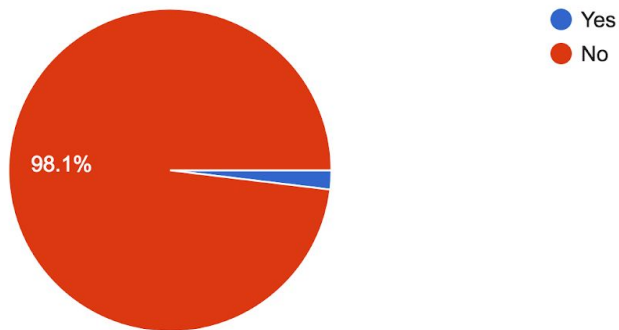
Have you lost any traditional HCBS services since 7/1/2018 ?

115 responses



Have you lost a fair hearing because you lacked Care Manager or Service Coordinator representation?

105 responses



What if anything do you want to share about the Life Plan?

62 responses

1. I don't know much about it.
2. Honestly there is no difference from our previous plan
3. My CCO knows less about the process than I do :(
4. We are waiting for the computer to do the I am assessment first
5. My MSC has continued as my Care Coordinator so the process has been sort of smooth for me.
6. I don't like the name at all. I mean can you plan out your whole life? Why should my son be required to do so? What if he changes his plans? The name suggests that because he has a disability that won't change, his life won't change, I find that kind of offensive.
7. Lacks person centeredness, providers not well informed of changes and the impact on their plans, meetings are way too long as provider work out fine details on merging life plans and staff action plans, providers have received limited guidance on staff action plans, technology is not working consistently- making long meetings longer, I Am assessment isn't picking up important details- which also leads to longer meetings.
8. I'm very hopeful as the information gathered from his I am will make life plan more relevant
9. Our Care Manager just copied and pasted from our ISP into the LP.
10. I don't think anyone knows how to complete one yet!
11. seems like it involves too much of my child's medical information and plans - things I do not need help with
12. Seem very much like the ISP with more health questions
13. It was comprehensive and addressed my child and her needs.
14. None
15. We will be completing it later this month
16. In Sept. we updated my ISP with the MSC--now that there are no MSCs or ISPs we were literally told yesterday we have to start from square one with a new Life Plan. That it will take up to two hours on the phone and more time in person. This seems like a terrible waste of time to start from scratch. Is there not one way for fields in the previous document (which exists in digital format) to transfer?
17. I'd like more information and an actual sit down discussion about the Life Plan and my daughter's services, and how it will change, if at all.
18. Our ISP was 04/18 and we have heard nothing official yet about the life plan
19. Confused about the whole change
20. We were told a life plan would be created but then the ISP remained in place and we worked on changes to the ISP.
21. Nothing
22. Because of my child's poorly understood disabilities, the life plan as the only instrument for which the comprehensive plan is managed has the potential for creating bias, misinformation and misinterpretation
23. I am concerned for my child's care when I'm no longer capable.

24. I can't say I have experience, but I can say that it sounds like bureaucracy and not person centered planning as per CMS regulations.
25. It seems to be progressing at a snail's pace. We are still waiting to hear about when the I Am will be completed. What we need more than anything is medical services coordination and I am still doing that long distance from my home in Maryland.
26. I do not know much about it yet
27. Don't know enough about it to ask how it will directly affect my young adult child
28. It's replacing the isp
29. I want to be prepared to fill it out. I went to the Manhattan DDRO meetings a few times last year to learn more about the entire process. That was how I learned about the process. I kept my MSC (who was new because the other one left apparently to do these new evaluations and personal circumstances as well.)
30. I completely disagree with the monthly required home visits. I do not have time for this and it is not necessary.
31. still learning
32. I don't know anything about it
33. All services my child receives, she received before the CCO. The Care Manager is uncommunicative and unhelpful. I will be asking for a change
34. Our MSC left her agency. That agency had a someone to cover until they "hired" someone new and that never happened and the coverage person left within a day due to pregnancy. Then, NO ONE RETURNED OUR PHONE CALLS. And to this day, no one has told us anything about managed care or life plans or anything. My son had to go to an RTF given his aggressive and challenging behaviors WHICH NO ONE HELPED US WITH. OPWDD and "emergency" means wait two weeks for anyone to call you back and then fill out this form.... really bad situation. They need to clean house and start over; put the money to the people, not to staffing more OPWDD employees who can tell you to fill out forms and do intakes. VERY BROKEN SYSTEM. I'm not for privatizing, but at this point, OPWDD is an agency that would make one wonder if it should be.
35. I haven't seen one yet
36. We are told it is replacing the ISP
37. There is a lot I do not know about it. Neither does my CCO
38. Have no info about a LIFE PLAN.
39. we are still in the process of it. I think it should be more focused on successful strategies in dealing with your loved one and should go more in depth about behavioral issues and long term goals.
40. Not all questions applicable about my child and had to leave a lot blank
41. I have objected to the CAS Assessment that was administered in Jan 2017 to my son and do not know where that documentation lies with the State.
42. The testing does not accurately depict his needs and I am worried it will have a bad impact on services to which he is entitled.

43. considering the invasive nature of the mandatory assessment, the 3 page form generated seems sparse and inadequate. it does not list true goals and very disappointing in general. in the process of revision
44. Not clear re this
45. I do not like all of the changes and how hard it has been for the care managers. Some are changing day to day and it is quite frustrating.
46. N/A
47. I'm deeply concerned that it is generated by what is input into the "I AM" assessment.
48. Wish I had a template or some idea of what the sections/format is
49. What is that? And how different from ISP plan. How the child's privacy is going to be protected
50. The delays getting a CCO and getting Self Direction approved are worse than ever for my family member as well as several of my own psychotherapy clients.
51. Not done yet
52. At present I am firing the CCO this better go smoothly as I am tired having no information & support has been so poor.
53. I nor my daughter's Broker can get a hold of the supervisor of this CCO. I am doing all the work to get services for my daughter. Very bad service.
54. I do not know if the life plan reflects what my son needs.
55. No set up for how to achieve goals. No accountability. No contact with sc.
56. It will be seated in a drawer
57. Our next group meeting will be a Life Plan
58. these plans are suppose to provide a customizable plan for the disable individual to live their best life rather than fitting a cookie cutter plan the insurance/CMS wants
59. Everything seems EXCEEDINGLY slow and no one really knows what's going on. Even the CCOs don't understand. And there seems to be a major backlog to even get a CCO.
60. It is not person-centered or individualized.
61. It needs to be more detailed and we need more services. Can't find respite workers there are not enough quality programs.
62. It's still a mystery.

What if anything do you want to share about the I Am Assessment ?

62 responses

1. What's the difference between the I AM and the CAS? Why do we need both?
2. I don't know anything about it.
3. We are waiting for the computer to do the I am assessment
4. It's ridiculously long and not necessarily appropriate for my child. For example, my child has autism and ADHD (and he's 11 years old) but he does not have mobility issues and his independence is already limited because he is a child. The I Am Assessment should not be one-size-fits-all, but perhaps it could be shorter if targeted to specific disabilities. If there are multiple disabilities, perhaps it is this one, but it could have been a lot shorter for my child.

5. started to try and fill this out but I don't know, don't remember and I'm not sure about a lot of things. I think I learned about the whole process first on the self-direction families list-serv and eventually my MSC/COO whatever told me about it but I really can't remember what, when and how. Also, I've had a lot of confusion. I thought we signed up for basic, the Care Manger says we signed up for comprehensive. But she says she's doing the I AM for us and only wants to ask us questions when she doesn't know - that doesn't sound right does it?
6. sounds way to complicated and poor use of resources with uncertain outcomes
7. Be prepared for a long meeting but it was a great time for really thinking about who my son is!
8. I have no idea what it is.
9. I don't know what this is
10. Way to long
11. My son lives in a group home. I am not 100% sure if he has or Has not done a I am assessment yet. I didn't think so.
12. It's essentially being done without me. Asked a couple of questions about my son's burial plans?
13. None
14. It was great and helped capture my son's preferences
15. I just learned about it yesterday from the new Care Manager but I don't know details. I'm definitely concerned about something she told me. She said that if your child has a developmental disability (mine does--autism) that the state now wants to newly delve into "mental illness" and test for that with a psychiatrist and track that. WHAT? And WHY would someone associate developmental disabilities with mental illness and WHY would the state want to track this and focus on this? Is not the chief goal of disability services to provide APPROPRIATE classes and services for families who (as families or as guardians) are responsible for determining what's needed with their own chosen team? Is the state to now align disabilities with mental illness? This is CRAZY! Many of us who have received Waiver Services for our kids for years (for us, almost a decade most of which has been with self direction) do NOT want the state to conduct it's own psychiatric assessments (to supercede what we have in place privately?), to draw false conclusions or make false assumptions about our kids or associate autism or other developmental challenges with mental illness. It's BAD ENOUGH the news does this. Every time someone does something horrible in the news they say "oh he was autistic" and people start falsely associating autism (specifically) with crime, with dangerous behavior and more. We have enough stereotypes to fight off. WHY is the state using this new I AM Assessment to pursue "mental illness" as if it's a global cover for all our kids? If someone wants to avail themselves of these addl. assessments or services fine, let that be a choice, but I'm very wary of this new "association" and profiling and also want to know who gets to see this--where the info goes (law enforcement? drug companies?). Autism is NOT mental illness but is mistaken for it way too often--let's not muddy the waters further. Ditto for other disabilities that mimic "mental" conditions. At very least families who have had appropriate and helpful Waiver services for years should be exempt from "new" mental illness investigations for their kids which might affect what they have or need--unless something is clearly warranted in the documentation--grandfathered, so to speak so you don't further "fix" what isn't broken (i.e what is working well).
16. We had the CAS Assessment, is that the same thing? I wasn't pleased with the CAS Assessment
17. I have no information. Therefore, I can't share anything about the I Am Assessment.
18. We do not know anything about it aside from the fact it is very lengthy. We are looking for a new CM our present CM knows nothing about SD and asked inappropriate questions about SD at our launch further indicating they know nothing about SD.
19. Again co fused about that also
20. I have never heard of the "I Am Assessment."

21. Nothing
22. OPWDD needs to communicate definitively that the I AM is not required for people in Basic.
23. It is the antithesis of person centered planning for people with I/DD as it doesn't address the long term community supports and the obstacles to getting them.
24. I don't understand it. We had someone come for 3 hours to do a CAS assessment. We had SSI intake, Social Security, OPWDD initial intake and more.... how many more do we need? This is on top of all our daughter's extensive medical assessments and reports that have been shared. This is becoming wasteful, time-consuming and emotionally draining.
25. Some of the questions were stupid and unnecessary
26. haven't taken it
27. I want to know specifics about how this document will be used to determine any services for my son
28. I have sat with families- while doing the I am assesment- most care managers do not know how to use the system- you can not pick more that two valued outcomes under my happiness -
29. What is it? How do I learn about it?
30. Some of the questions for my son were inappropriate and completely irrelevant for someone his age. A complete waste of my time.
31. No
32. ?
33. When the hell will my child get this
34. I don't even know what it is.
35. It should be a program a parent can fill out at their leisure and ask for assistance if they require it. It is not user friendly for the participant.
36. Have only seen it in a professional Broker capacity. Many of the questions are ridiculous
37. I hope that NYS will stop trying to fix things that are not broken. I AM is a bunch of malarky and unclear in its questioning. It is also very invasive. I do not understand how the information will be confidential. Where does it go? Who or what entity is in charge of protecting privacy?
38. Have not done it
39. It should have more focus on realistic future goals and current issues that are not being addressed.
40. Not sure if it will be beneficial for my daughter's needs. Will know in the future.
41. I don't know anything about it other than references to it from general public meeting about the CCO roll out. BTW I was JUST contacted by my Case Manager a week ago after I initiated contact with the CCO's ED (!) over a month ago because a phone message was left at my home with no reachable number.
42. In response to earlier question- Have you ever been told ANYTHING about the "I Am assessment" from OPWDD or your CCO/HH?" the answer is yes. Have we been told much-NO!
We have not yet participated, but were just informed today that OPWDD has mandated that it MUST be completed by Dec 31--. We are mostly concerned about the lack of communication about how this information might be USED to determine level of support needs...or types of supports or recommendations from a future, yet undisclosed managed care team with a yet undisclosed set of procedures. While it might be better than the planning tools previously used by traditional services, no one should fool themselves to think that this interview can possibly substitute for a well developed person-centered planning process!! have no idea what is going on.
43. I don't even know what half of these terms are.

44. took over 2 hours and demanded a lot of irrelevant or invasive information. the computer program was troublesome and it is unclear why i needed to disclose the type of burial my son would require.
45. Not enough info
46. Too much ridiculous information asked...why do they need to know my 13 yr olds funeral plans or what scent candle she likes?
47. N/A
48. I am very diligent about keeping informed and was lucky enough to get a peek at a pretty comprehensive list of questions on the I AM assessment through a local advocacy group. Because I knew ahead of time what the different sections of the assessment were, I was able to question my Care manager as to why certain questions had not been asked that were highly relevant to my son's case. She went back and ticked a box that had been left unticked and the entire section I had been referring to appeared on the screen.
49. There were also a couple of occasions where we were forced to choose a single option when 2 or more would have been appropriate. I was later told that this was a glitch and that the MSC/Care manager would have had to scroll to another section of the page to be able to check multiple options. I haven't been able to ask for this change to be made to my son's assessment.
50. Long and not sure what the impact is on child's current services.
51. What is an I AM assessment? Do not assume that everyone understands the abbreviations.
52. Not yet done
53. I never got any information
54. It was haphazard because the technology was not working properly.
55. Not beneficial. Goals are to remain safe and have family member present.
56. Nothing with mention of obtaining equipment or necessary resources.
57. Too long, too useless, better to play guess
58. .?
59. seems to want the individual to conform to whatever ideology CMS is wanting rather than accepting and supporting the real individual as their self
60. It seems to have an institutional bias. What I paid caregiver would need to know vs. information that would generate a truly individualized Life Plan. Even in that regard, it is lacked. E.g. asks about dental hygiene but omitted an inquiry pertinent to my son.
61. A lot of it did not apply to my daughter. It appears to be created towards folks that have a higher skill level.
62. The I Am form is 62 pages of questions that seem to have been prepared by someone who never met a person with a developmental disability. The form poses broad questions but offers limited choices for answers which do not allow for an accurate description of the individual. Since this information will subsequently be used to determine what services an individual will receive, the limited choice of answers will surely result in service cutbacks.

Please Provide Your Feedback about the Transition from MSC to Care Manager ?

100 Responses

1. is whole thing is an unnecessary process, needless complicating the lives of disabled people with an additional layer of essentially-meaningless bureaucracy.
2. care manager less available
3. Too rushed, technology wasn't ready, not enough training available on what really matters, not enough education for providers (hab providers)
4. We had no issues transferring
5. Confusing
6. Care Management was designed to manage medical and mental health care when others were misusing services/having too many ER visits. I dislike that model is now carrying over to the OPWDD world. A default consent form for the Care Management has a sneaky line that basically says "All doctors or PCP" before we lost our current doctors. I crossed out that line as I don't need our Care Manager harrass our PCP when I am perfectly competent to manage my son's medical care. I prefer to scheduling doctor's appointments for when I am available and not if or when our CM wants us to.
7. It hasn't been rolled out smoothly, but OPWDD was given an unrealistic time frame to complete the transaction.
8. It's been very poorly managed. I had more info than my MSC/care manager did.
9. the only reason I know my Care Manager was that I reached out to my MSC on her last day, and she forwarded my info to her and cc'ed me on it! But there's been no outreach from the Care Manager since the transition.
10. A shameful disaster.
11. Nothing to report - took two months to get a care manager and have had one meeting after screaming and shouting with excessive emails all over and to everyone concerned at the agency that dumped us.
12. Very easy
13. Sloppy and poorly managed. Feel lucky that my MSC is also our CCO! Many people got lost in the transition and still do not have a CCO.
14. My MSC became a supervisor and I was given a new Care Manager, I have worked with her in the past as a temporary MSC . So we are able to work together to get any paperwork done. I am sure we will do the I am when they are given the computer they need to do this.
15. I believe thty sure OPWDD already knows about all of the problems you're "identifying" with this survey. Advocacy groups should be focusing their efforts on helping to get things on track rather than complaining about things via a survey.
16. terrible - for a while i didn't have her proper phone number or email - even though she had been my MSC. She had me sign a paper for the higher level of coordination without presenting me with

the Basic option. I requested to be on the Basic plan because I don't need constant coordination nor help with medical issues

17. Too little or non information have been given to me about it
18. It wasn't any big deal for me because Linda Schellenberg found me a new MSC since my MSC left right when the plan was changed and I really depended on Linda and my new MSC to take care of everything and I trusted them and I still trust them but I'm lucky.
19. It has not been smooth. I had to reach out for the name of my care manager. Did not have one until almost Sept. There is confusion about my son having basic - that he should have comprehensive but could not get an answer as to why. With SD not sure I how much help I will need to help us - only need help at this point if FI says need the care manager involved.
20. Both the MSCs and consumers are not given enough information
21. Families need to be more informed about the Life plan, I Am assessment and privacy rights
22. So far there have been no issues.
23. In my case it is the same person.
24. I have a great MSC and she has answered every question I have had and provided guidance.
25. None
26. Our care coordinator has been great; we've had a seamless transition process
27. A bungled mess. Nobody at SKIP knew WHO would be helping us. There was initially a hope that supervisors at least might be watching our kids' "cases" but then we learned last minute that would not happen because there were different levels of care and no supervisor could take on a caseload that would "conflict" with that (which makes no sense) and that supervisors in Manhattan (SKIP was in Manhattan) could not help Brooklyn families (SKIP served all boroughs). The letter I got had no emails for the Care Managers. I figured it out (from the email for the higher ups) but this is the 21st century and having an email contact is important. Also, nothing in the letter said anything about what would happen, how services would continue. Our new care manager was very nice but had no idea about my daughter (at SKIP new MSCs were supposed to read the case info to become familiar with those to whom they were newly assigned) OR about what records were or were not transferred from SKIP. She later (on the call) was able to look up to see that her records were "up to date." It seems that we parents are in for a LOT of work ahead to accommodate what seems to be a clunky, invasive, and possibly far less personalized system
28. I think there may have been conference calls about the transition which I was unable to attend and now I feel completely lost
29. No one has actually explained anything. That's why I am possibly interested in a new MSC.
30. These ridiculous acronyms are nothing but medicaid speak and is shameful evidence of why you-OPWDD bureaucrats should get off the states' payroll and stop making my ability to take care of my daughter more and more difficult and complicated. This is nothing but BS . Nobody on this planet has ever heard of life plans, DDP2s , CCOs. - under the guise of some medicaid program ? Shame on you. I pray for day soon that this entire process becomes subject to the federal courts so that this BS will stop .
31. CCO yes care manager no. We want to move on and would prefer no setbacks for being honest.
32. It seemed as if the MSC did not have all the information in order to provide it to me.

33. For our family it was smooth. The agency providing MSC services contracted with the CCO for one year so that all our services and contacts would remain the same for one year.
34. We have had three Care Managers since August. So far none of them have been able to explain the program. The second one knew absolutely nothing and couldn't answer any of my questions
35. I had to email to find out who my care manager was..no one told me anything
36. impersonal with many delays in getting important services
37. I haven't been able to get any of the approved services and the coordinator rarely returns my calls/emails.
38. I feel that we have been somewhat protected during this transition because our former MSC agency (Job Path) took advantage of the 1-year transition period. Our current Care Manager is, fortunately, the same person as our former MSC -- and is still "housed" at Job Path. This has at least provided us with some consistency during the transition period. Once we lose the connection with Job Path, I have no idea what will happen. Probably nothing good. Advance Care Alliance has been inaccessible by either phone or email.
39. My son's MSC is still is care manager. And that is a good thing. Paperwork is still trickling in. No new service or support is provided in this CCO structure that would provide my son with additional supports or services. Nor does this process speak towards the sustainability of Self-Direction, as it was billed by OPWDD
40. Parents need a newsletter monthly from the CCO telling us what the progress has been. I cannot see how Life Plans will be completed by July at this rate, nor when I will have someone in New York overseeing medical care.
41. This transition has been onerous and far less than satisfactory. The new "people" we have met to represent CCO have not been prepared and instead of helping us have made the situation more difficult. In fact, some of her questions have been insulting and made it clear that she had not read the extensive paperwork on our daughter's situation.
42. Had a Msc for my younger son with head injury assn for nine months that I was happy with and wanted to transfer my older son who was with citizens and was dissatisfied with to head injury provided I would have the same care coordinator for both boys. Head injury was made aware of this a few months ago and told me they would give both boys the same care coordinator My older son was going to be transferred to head injury on Sept 1 which eventually turned into October. 1. On October 9 head injury tells me that my care coordinator was promoted to another position and will no longer be serving my two sons. I was given a new Care coordinator for both my boys who does not have much experience and Is not too knowledgeable about things. I also had an annual isp meeting for Both boys in October. NOW after doing the I am assessments I am told that I Did not have to have isp meetings but still have to have family care meetings for Both boys by the end of December which are currently scheduled
43. Our transition was fairly smooth - we knew what to expect We did have a change I care manager(our care manager , formerly MSC was promoted to supervisor) but that went smoothly as well We did not attempt to get any additional services (don't need any at this time) so can't

answer the question about service acquisition. Still have all the same services as before - no loss/ no gain. We experienced little change with the conversion to CCO

44. it is BS
45. Awful... received one phone call where was notified my MSC of 3.5 years was no longer going to be working with us because she was assigned to only Tier 4 people. There was no transition time whatsoever ... and i now understand the Tiers were not even properly determined as there are level 4 individuals that are inaccurately placed based on how questions were asked in the Tier process. We have invested time into our team and into the relationship our child has with his MSC and are very sad about the change that we had NO say in.
46. Disaster. Total confusion, no one knows much about anything.
47. I learned about the life plan and I am assessment from Non OPWDD parent groups. Not from my MSC. You left out the evil CAS. (Consolidated Assessment System) we did a CAS for my daughter when I read the assessment Most of the info collected by OPWDD's professional was wrong. It made my child much higher functioning than she is
48. Could have been handled better.
49. I have little information. My son's previous agency stopped provided care manager with no notice to us. Received a call from someone saying they were from his CCO- nothing in writing and we are still waiting. Very worrisome!
50. Personally I read all information from opwdd that is now I am informed
51. It has been extremely difficult to contact the MSC to find out anything.
52. My child turned 21 in July so we had already set up the dayhab etc but it's almost like we had to reapply. There was no set system for the transition. When we needed paperwork that I didnt even know we needed, there was no way to get it from the CC Agency- Tri[something]. It was through my persistence that the Dayhab intake person helped us coordinate getting some form uploaded to the platform that the CC orgs were using. TriCounty was not up to speed where as the CCorg (I think ADAPT was and through this connection we were able to get my kid into the system. The CCCs were very frustrated as well. Infact they still use the old agency email because they do not yet have one for TriCounty. Also I am signed up for comprehensive level rather than basic and am not sure what to do in this regard . Also almost approved for SDirection .
53. I still don't fully understand
54. It had been terrible being that my care manager has been changing on an almost months basis. I can better answer this question after I get to know my new CCO.
55. It seems shaky at best
56. My transition was smooth. Because I work in the field and understand the system I have not had any surprises yet. I am sure they are coming. In terms of communication and roll out and how the transition occurred without full comprehension of stakeholders, that is not only a wider problem for the system but also the indifference of families'.
57. I dont understand what is the difference ,its seems to be just a name change
58. Very frustrating I'm still with out services
59. Effectiveness boils to the person, not the position title. We had a great MSC, and several lousy ones. This Care Manager is lousy, but I think it's because she's overwhelmed with cases.

She even gave me the wrong email and didn't correct this until our broker contacted her supervisor. This took over a month This transition hasn't improved care. It won't until there is adequate staffing. And better hires

60. I am disappointed that my Care Coordinator, who was also my MSC, is not helping with medical/health care of my child. I still have to do everything myself. I don't see any improvement yet with the new system, which was supposed to go into effect back in July
61. Transition is always very confusing
62. It has been terrible. The agencies were not prepared and I am sure OPWDD was hoping for some kind of attrition which is terrible and causes problems for the people who need us most. My son has been suffering terribly in the past 2 years and OPWDD has been absolutely useless (as the state and all supports BTW). If you want to talk, you have my email. I just need to support my son's crisis now and try to get to the next phase which is moving him to housing. and no agency will want him because he can be aggressive and is considered a "high needs" case. Sorry, I could go on....thanks for doing this and I hope it gets somewhere. Note that I do believe there are really good people at OPWDD- it is just mismanaged and NOT transparent.
63. When transitioning from old to new, my receipts for family reimbursements were deemed ineligible because of the timing of the receipts. My MSC was supposed to be my care manager but he was promoted. The new person is okay.
64. We are fortunate our care manager is experienced and knowledgeable. Unfortunately, that is not the case for many. The new care managers are very confused and so are parents. There is no up to date information for the brokers who will be completing the action plan.
65. I feel it should have been rolled out and explained in a much more detailed format than what was provided to families, Care Managers, Individuals and their families. In my professional role, most MSC's were still quite confused themselves and were unable to present a detailed explanation of the switch to CCO, leaving most of the families I deal with very confused and not understanding the changes being implemented.
66. Very Rocky. Had 3 interim people so far since change from MSC. Meeting NEW Care Coordinator after Thanksgiving. Scheduled to do I Am interview.
67. My son is a tier 4 so we have started this with our msc. I have heard many labeled with tier 4 have lost their msc. So far we have not. We are still in need of hands on services for crisis behavior and have staffing issues- same as before.
68. Seems too difficult to manage the IAM APP and now am having a longer wait time to reach my Care Manager
69. I am greatly concerned about protecting my son's personal and confidential information from those who seek to profit from the CCO/ managed care "roll out."... Last May we were informed by letter from our former CMS agency about the CCO transition but our MSC did not know a lot (did anyone?!) In June during our meeting with the CMS I/my son refused to sign a HIPPA release to have his privacy data shared with anyone other than the previous MSC's agency. In late August or September we were informed of the identify of the new Case Manager by the soon to be former CMS agency and assured that the person who would be leaving to work for the designated CCO was briefed on our privacy concerns. In late September two messages were left on our home

telephone machine but the number that was left did not have any identifying information and I could not reach anyone on the number. I eventually emailed the CCO's ED and was contacted a week and a half ago by a supervisor for our son's new Case Manager. During a scheduled call last Monday, the supervisor informed me that the Case Manager had been changed and that she could not speak with me about my concerns until I produced a copy of my P of A (which should be in any file maintained by providers...). I suggested that they get their HIPPA release to me and my 26 year old son before we talked to them. (I also expressed concern about their having changed the Case Manager over the weekend after confirming the identify of the person who had been provided to us in August.) We have received NO WRITTEN INFORMATION from the new CCO except the email from the Case Manager introducing herself a week ago. We know nothing about what is supposed to be happening now.

70. Horrible. The agency told us we could not have the basic plan. We were dumped by the agency without warning two days after they demanded a meeting to update the ISP. Now I need changes to the ISP and the agency didn't handle it. New CCO knows nothing about us or our history. No ISP and it is now out of date. So, do we lose services because we are out of compliance??
71. for us it has been relatively smooth, since we maintained the same who has worked with our son for many years (from a quality organization). So far, care Design has seemed to be relatively responsive -- Less than one week into the transition, they announced that "supervisors" would not be permitted to have a case load of their own...which would have meant a change in CM for my son-- absolute contradiction the the promises made about "transition with your MSC!". After pushback from CM and from families, Care Design reconsidered and permitted supervising CMs to keep some participants on their case load. However, It has been disturbing that OPWDD seems to send out new regulations to the CCOs and the CM at the last minute, with new rules, procedures or expectations.. with little lead time and sometimes with little rational. MANDATEs regarding frequency of visits (monthly) for tier 4 participants, and mandate of Dec 31 IAM and Lifepans ordered by OPWDD, with little room for negotiation... putting extraordinary pressure on CMs and mandates on participants before many of the kinks have been ironed out, or the procedural questions and challenges have been answered.
72. My previous MSC is my current Care Manager
73. it is unclear what has changed or what services, if any, are now included or removed. i am not even sure to what extent the manager is supposed to managing. I am greatly concerned that the manager will not be independent assessors of my son's needs and will be pressured to cut or disallow vital services in order to lower their budget to my son's detriment. The "transition" has not been clear to any one i have discussed this matter with, in any capacity. i still do not know the extent of the "management" that is to be provided. the primary obstacle of not having appropriate and adequate staffing remains constant. I am just glad that the much needed services that i have been able to put into place have not been disrupted and the case manager is bright and truly trying to help.
74. Confused!?

75. My MSC was promoted shortly after she switched to being my care manager. I have yet to meet my new care manager.
76. Confused everyone is confused
77. Went to a number of meeting on the transition to CCO and Care Manager
78. I have not spoken to the Care Manager since the transition took place. I was successful in changing my son's day hab program in late August, because I submitted most of the required documentation myself. I emailed the MSC/Care Coordinator to request that she forward the one or two items I did not have access to. As far as I know, she did that because the new program has not indicated otherwise.
79. The only contact I had with her leading up to 7/1/18 was when she needed me to sign the enrollment paperwork. I have not spoken to her since.
80. As the change was happening in July of 2018, my MSC quit the agency we were using, giving very little notice and we were left without an MSC or a Care Manager. I had to raise holy hell with supervisors at the agency to get assigned a new Care Manager. It was terribly stressful.
81. My daughter has been designated Tier 4 - highest need - yet the care manager assigned by ACA has no experience with Medicaid and has not been trained. If we lose Medicaid benefits owing to this it is just a lawsuit waiting to happen
82. Was just told what their recommendations were, cookie cutter approach, not based on specifics of child or type of family/ need/ interest
83. My child's medicaid was terminated by the error of HRA in September, when I called MSC/Care Manager, I was told because I signed up for the basic plan, they do not need to do anything. I heard from other parent that if I do not sign up for the comprehensive plan, the care manager would not help in keeping the straight medicaid. I was told the parent needs to be on the top of everything, if I have a basic plan. I would like to know why MSC/Care Manager so badly wanted me to sign up for the comprehensive plan, what is the difference between comprehensive and basic plans, and what is the advantage for signing up for the comprehensive plan if I want to pursue the self-direction. I also would like to know what is the future of the self-direction would be.
84. If it were not for my broker who is an independent, I would not be aware of any of the things mentioned in this survey. I learned about the I AM Assessment from my broker and another special ed parent. I have had 3 different care managers since 7/1/2018. One of them set up an ISP meeting and quit and (Head Injury) never told us. I had a room full of people and no care manager.
85. Terrible for the many families and consumers who I know. The new system was reinventing a wheel that just needed to be oiled, not replaced. Too many lives are affected and the people staffing coordinated care and services have been turned upside-down.
86. I AM ABSOLUTELY ADAMANT ABOUT ENSURING MY PRIVACY AND THAT MY EMAIL IS NOT ASSOCIATED WITH THIS SURVEY SO PLEASE TAKE THE REQUIRED PRECAUTIONS. The transition has been disturbing on several accounts. Our new care manager informed me he can not find certain required paperwork for my child. They came over for a meeting and I asked them if it was a circle of support meeting or a semi ISP and they didn't know. They didn't know why they

were there. It was their job to know that. My care manager has told me he is available for any help needed. However when I have asked for help there is no response. He is brand new and so is his supervisor. I miss our old organization which seemed to understand what the requirements are not to mention getting help. I do NOT want to have people coordinate my child's health needs. I do NOT want monthly meetings and that's what I would have gotten if we chose comprehensive due to the nature of the disabilities. So now I have NO help with coordinating / getting needed OPW services. The transition came with an ultimatum that I would have to also have my child's health care needs coordinated. The time issues for this are ridiculous. I do NOT want or need monthly in person meetings. I can not lose the time from work for that! I do NOT want a four hour IAM assessment. It is an invasion of privacy. I have yet to see how any changes that are instituted will help my child.

87. All the information I got was when we were doing each step. I'm sure there is information I haven't been given yet.
88. Didn't expect anything to change for the better as the MSC was never around or helpful. No surprise, she is the same. Months on end we don't hear from her & if I call her goes to voice mail & maybe she will call back. She is not informed herself yet prides herself working 17yrs. as a MSC. We moved & she didn't want to change address do to all the paperwork. I could go on & on. There is much more that I think is more serious but I don't have all the time since I am doing all.
89. My son has had so many MSCs who really do not get to know him. The Care Manager did the assessment on the first day she met my son.
90. I don't understand why this is necessary
91. Had no sc for several months. Told to contact supervisor with no response until the third message. Not happy with the program at all. Over three months without contact from sc then told our stuff put on hold for more needy participants
92. Waste of money. Needed "I don't know" or "not sure" to answer most of your questions in this survey. They won't listen to this survey anyway. Life Plan for me is due by Dec 2018, more ridiculous.
93. I was never notified that I had been assigned a care coordinator (We went from SKIP of NY to ACA). Meanwhile, our LOC was about to be overdue. I had to call/email Ellen Bleckman at OPWDD for help. Her office provided me with contact numbers. Nigel Nero at ACA got the ball rolling. I met with Tanya Brown, the care coordinator's supervisor, and the care coordinator (who did not say one word the entire time). The LOC was completed. The first care coordinator then was moved off my case and I was assigned a second care coordinator. She is incompetent (I asked for an ISP amendment and sent her a draft. She said she completed it and sent it to my FI and Broker but they never received it. She didn't know it had to go to me as well. She couldn't operate her own computer to complete the IAM assessment and she is unresponsive to email). I asked Nigel Nero to assign me another care coordinator. He has reached out to Gabriella Medina, who is the supervisor for my area (Brooklyn) and I am supposed to hear from her asap. If I don't hear from her in a timely manner or if the new CC is incompetent, I will lodge a complaint and switch agencies.
94. Went fairly smoothly for my two.

95. No choice, just moved past it
96. No one knows what's going on.
97. I changed CM on 6/30 because then MSC wouldn't confirm that she was continuing with CCO.
Then abruptly lost the new CM and notified of that in early November. Because my son is Tier 4, Life Plan has to be completed by `12/31.
Not likely to yield an accurate or helpful document.
98. Not enough information was given and I still don't see the benefit of this transition. I know the federal government made New York do it but I don't see any new Programs or services being offered.
99. It seems we are adding layer upon layer of bureaucracy, the cost of which will reduce funds available for actual care.
100. Seems like there is more to it than I am aware of. I will discuss these with my care coordinator.

doh.sm.1115Waivers

From: Duffy, Christine [REDACTED]
Sent: Monday, December 3, 2018 6:42 PM
To: doh.sm.1115Waivers
Cc: Pizzurro, Josephine; Fardella-Roveto, Elvira
Subject: 1115 Public Forum Comment

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Dear Project Approval and Oversight Panel:

St. Mary's Healthcare System for Children joined the One City Health PPS in 2015. Our partnership with the One City Health PPS has allowed us to expand multiple services to the most vulnerable children in New York. The One City Health DSRIP PPS has provided funding for St. Mary's to create and run a Community Health Worker (CHW) program that enables our CHWs to conduct home visits to pediatric asthma patients referred to us from Elmhurst Hospital. To date, we have made almost 200 visits to conduct home environmental assessments, to help educate families on how to reduce asthma triggers in the home and to make additional referrals to the Integrated Pest Management service made available through the One City Health partnership. These visits often also result in helping families resolve other social determinant of health issues that may not initially be evident upon referral. We would not have been able to create and sustain this program over the past two years without the help of the OCH team. We meet with the team at Elmhurst and with the team an OCH monthly to check progress, share goals and success stories and to learn where we can continue to fill gaps in care. All of this results in improved health, less missed school and work days for these families and for the children in our care.

The abundance of free trainings and webinars the OneCity Health PPS provides are invaluable to our staff. OCH paid the membership fees for multiple St. Mary's clinicians to become members of the Center to Advance Palliate Care (CAPC) – a resource we could not afford without the OCH funding. Since the population we treat is medically fragile and complex children and young adults, this is a resource we tap into daily to help us deliver the best care and comfort to the families of these patients. Multiple St. Mary's team members have also attended trainings on Motivational Interviewing, Cultural Competency & Grand Rounds led by clinicians. The creation of the OCH Learning Management System and its availability to our staff is another significant benefit for our staff. On December 14th we will be sending a team of care coordinators to attend the OCH sponsored event to address housing needs and safe living environments for clients, presented by LEGAL HEALTH – it would not be possible for St. Mary's to arrange this unique and valuable training on our own.

The leadership at One City Health has also helped us create new collaborations with other partners in their system. We recently met with a team of clinicians at the Complex Care Clinic at Bellevue Hospital to collaborate with them on a partnership to further engage & educate patients & clinicians about opportunities to enroll patients in a Pediatric Health Home; patients who join benefit by having a case manager assigned to help them coordinate their care. By attending several OCH sponsored PAC meetings and events St. Mary's has been able to network with other providers and build new relationships that have resulted in better care for all patients.

OCH is always open to new innovation and ideas and we have reached out to the PPS team on many occasions to ask for their guidance, support and feedback. We know we will continue to build on all of the relationships we have developed with OCH's help in order to be able to sustain all of the great work that has been accomplished to date.

Thank you for this opportunity to provide feedback.

Christine Duffy

Project Manager, Strategic Initiatives

St. Mary's Healthcare System for Children

5 Dakota Drive – Suite 200

New Hyde Park, NY 11042



www.stmaryskids.org

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From: [REDACTED]
Sent: Thursday, December 6, 2018 9:54 AM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment
Attachments: 1115 waiver public comment 12.6.2018.SOYAN.pdf

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Attached please find the public comment of SUPPORTING OUR YOUTH & ADULTS NETWORK-ADVOCACY WORKING GROUP

Leslie Feinberg
Organizer/Family Peer Advocate
SUPPORTING OUR YOUTH & ADULTS NETWORK
Name updated to include the lifespan
[REDACTED]

SUPPORTING OUR YOUTH & ADULTS NETWORK (SOYAN) Advocacy Working Group welcomes the opportunity to provide public comment on the 1115 Waiver in response to the MRT's public hearing held November 29, 2018 in Manhattan.

SUPPORTING OUR YOUTH & ADULTS NETWORK (SOYAN) is a grass-roots network of over 200 parents, professionals and self-advocate individuals residing on Long Island focusing on empowerment and advocacy issues relating to supporting the journey of youth and adults embarking upon living a self-determined life with the supports of Self-Direction through OPWDD. **SOYAN is committed to the sustainability of Self-Direction with Full Budget Authority.**

We call attention to the full scope of the roll out to managed care because it is SOYAN's mission to address the needs of individuals with intellectual/developmental disabilities (including complex chronic medical conditions) who rely upon Self-Directed services and supports with Full Budget Authority. Since Home and Community Based Services remain at the cornerstone of Self-Directed supports and services, any transition from HCBS under OPWDD 1915c waiver to the 1115 MRT Waiver Managed requires full scrutiny. SOYAN stands in agreement with the public comments submitted by Disability Rights New York (October 3, 2018) and NYCLU and NYLPI (October 17, 2018) relating the 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).

There are several issues that demand our attention:

1. **SOYAN is concerned about the sustainability of Self-Direction with Full Budget Authority (SD-FBA) within the proposed managed care system.** We are very concerned about utilization management, and any attempt for the managed care organization to remove the authority of the individual to set rates of pay for self-hired community rehabilitation staff or to adjust how the individual allocates staffing hours within their individual budget, as well as the selection and distribution of other supports and services, that fall within the current approved options as outlined in the Self Direction Guidance for Providers (March 2018).
https://opwdd.ny.gov/sites/default/files/documents/SD_guidance_030818%20%28002%29_0.pdf
If the SIP-PL is given these powers, it will dilute the intended person-centered and individualized support and service of SD-FBA.

- a. **SOYAN makes note of inconsistent and confusing information about how SD-FBA is presented within a variety of public announcements and forums .**

For example, the SIPs-PL states:

“OPWDD is committed to continuing transformation goals related to self-direction. The SIP-PL benefit package includes the self-direction benefit. While the SIP-PL will oversee the benefit, the self-direction program rules will not change, and will operate in Managed Care as it does in the Fee-For-Service program.”

https://www.health.ny.gov/health_care/medicaid/program/medicaid_health_home/s/idd/docs/sipspl_qual_doc_with_attachments_final_draft_for_public_comment_8_31_18.pdf (p30).

Yet, other indicators seem to suggest that the move towards utilization management will put decision-making regarding individual's Self-directed supports and services into the hands of the MCO rather than maintaining SD-FBA:

SIPs-PL will use Medical Necessity Criteria (MNC) guidelines as defined in New York Social Services Law, § 365-a to determine appropriateness of new and ongoing services. (p 36)

- b. **It is the position of SOYAN that SD-FBA is already capitated with a budget set by assessment and Personal Resource Allocation.**
- c. **There must be a clear definition agreed to by experts and stakeholders for “medical necessity of habilitative care”.**
 - i. Given that characteristics and ongoing support needs of individuals with developmental disabilities, what is meant by “medical necessity”?
 - ii. Will OPWDD and DOH set standards for all managed care organizations to follow and govern such standards?
- d. **Will Community Habilitation services at the foundation of SD-FBA be removed from the 1115 waiver and placed into a new diluted waiver?** The Community Choice First Option waiver is set to roll out in January 2019. While the current plan for Community First Option does not include individuals with SD-FBA, what assurances can be provided that SD-FBA will not be lost with upcoming rollouts?

SOYAN contends that the NYS Department of Health (DOH) within the MRT 1115 Waiver should clearly and plainly state that people with SD-FBA should have an individual budget. This should be clearly affirmed by both DOH and OPWDD in all and every published document.

2. **The transition to the Care Coordination Organizations has been wrought with challenges.** The first step in preparation for the movement to managed care was the establishment of **Care Coordination Organizations (CCOs)**, mandated to begin this past July 2018. Given the outcry from individuals, families and at times the care coordinators themselves, the I/DD community remains vigilantly concerned about the erosion of supports and services that provide community integration and living conditions that promote true quality of life, pursuant to OPWDD’s mission statement.
3. **SOYAN is very concerned about the design and planned utilization of the Coordinated Assessment System (CAS)** There are numerous concerns about this process that can be discussed in greater detail elsewhere, but SOYAN’s major concerns are highlighted here:
 - a. Families and individuals and service providers who have participated in the CAS have reported repeated frustrations in the process and outcome. They report that although the examiner asked numerous questions, which were answered in detail, the summary report was inaccurate and misleading, even on very specific facts. SOYAN is very concerned that there is no opportunity to review how individual items within the 200 questions were scored by the assessor, and thus to validate the accuracy of the assessor’s judgement.
 - b. The reporting of events that actually occurred within the three-day reference period represents a limited and potentially biased picture of the individual. Furthermore, it ignores the interpretation that critical challenging behaviors might not be occurring BECAUSE the person is currently receiving appropriate supports. This is critical in the case of individuals with a history of challenging behaviors who are currently not exhibiting those behaviors because they have individually designed and maintain intensive appropriate supports. SOYAN is very concerned that the inability to code that kind of behavior will reflect a lower need for intense services and thus deny the person the supports that are critical to them, thus resulting in an increase in the problem behaviors!
 - c. I/DD is a life-long condition, but with appropriate supports, skills can be learned. There remains no written protocol that addresses or acknowledges this fact.
 - d. The CAS validity study purports to show validity but it does not. There are multiple serious research design flaws and concerns that may be discussed in future public comment. Similarly, there does not seem to be adequate attempts during the development and implementation of the CAS to demonstrate adequate reliability.

- e. The CAS/UAS needs assessment is the system NYS has adopted to meet the requirements of managed care rate setting and resource allocation at the system level. Predictability is the form of validity central to this purpose. The CAS validity study does not address predictive validity whatsoever.
- f. The recent proposal for SIP-PL did not address the impact of using a needs assessment (DDP2 or CAS) to develop an individual budget for SD-FBA (Personal Resource Allocation-PRA). It appears this is inconsistent with the way managed care functions. PRA was not specifically addressed in the SIP-PL or in any document related to the 1115 waiver that SOYAN members could find. Will the PRA still be used to determine budgets for individuals with SD-FBA under the 1115 Waiver?

4. OPWDD stakeholder engagement: The process for educating individuals and their families with clear and concise and substantively accurate information regarding the roll out of managed care has been extraordinarily fragmented, disjointed and disingenuous.

- a. Families have been provided with little or misleading information, including threats of loss of services if an individual with a SD-FBA plan did not enroll in the offered health home care coordination.
- b. CCOs have been unable to retain care coordinators or train them to minimally acceptable standards, resulting in many families being ignored, shuffled or misled, often asked to engage in assessments (I AM) or Life-plans with care coordinators who have been minimally trained in their implementation and with no prior relationship with the individual.
- c. The last three webinars designed by OPWDD to inform families and individuals about the basics of Self Direction (9/25), the CAS (10/29) and Managed Care (11/28) provided platitudes of empty reassurances, scant information or explanation, and evasive responses to the questions and concerns of family members.

SOYAN has embarked on a petition addressed to NYS legislators to require the document addressing policy and standards of SIP-PLs expected to be issued by DOH and OPWDD early next year be:

- written in clear and concise language,
- have an executive summary that outlines the substantive changes and
- provide education opportunities prior to the release of the document.

SOYAN will continue to engage with community members to secure more allies. These signed petitions have been sent to the chair and ranking members of both house's committees responsible for oversight of OPWDD and DOH.

SOYAN has repeatedly requested monthly meetings among OPWDD and DOH with all established family advocate groups/individuals that have also been submitting public comments together with the same opportunity and at the same time to dialogue about the changes as they evolve.

To conclude:

As noted by the combined SIP-PL comments of NYCLU and NYLPI referenced above, “[f]urnishing long-term supports and services is not the same as providing health care. Successfully supporting people with I/DD means more than buying and selling services...Supports and services provided must promote the efforts of people with I/DD to have valued lifestyles in their community” with a structured set of social and executive function supports. **Self-Direction with Full Budget Authority (SD-FBA) must be maintained within the framework of OPWDD supports and services.**

From: Civics League for Disability Rights [REDACTED]
Sent: Thursday, December 6, 2018 10:32 AM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment

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**Testimony of Sharifa Abu-Hamda
New York State Department of Health
Public Hearing on 1115 Waiver
New York City
November 29, 2018**

I appreciate the opportunity to comment on the 1115 Waiver. My testimony will address the problem of insufficient funding within the managed care program of services required for people, like myself, with high needs.

My name is Sharifa Abu-Hamda. I live in Brooklyn, New York. I have a degree in accounting, work full time and serve as President of the Civics League for Disability Rights.

As a woman with a progressive, degenerative disability that limits my movement and affects my health in many ways, I receive 24 hours of personal care in 12 hour split shifts, 365 days a year.

Without 24/7 personal care, I would not be able to live independently and would be confined to bed, in an institution. I would not be able to work and would be dependent on SSI.

In 2012 it was determined that due to my disability my body was not getting sufficient oxygen and my doctors prescribed a ventilator for me to use at night in order to remedy this. My nighttime personal care worker makes sure that my ventilator is working properly and that I am breathing properly. She also changes the tubing and heats water for the humidifier needed to keep the air I breathe moist. If my home loses power she can replace it with a backup battery, ensuring that I am able to continue breathing.

I also require a cough-assist machine in order to keep my lungs clear. This equipment is expensive but it is needed, especially during the change of seasons when people are prone to getting sick, to prevent me from getting life threatening pneumonia and other infections. My nighttime personal care worker manages the machine and puts the mask on my face every night and morning in order to keep my lungs clear.

In addition, my nighttime worker turns me multiple times each night to protect me from getting pressure wounds and assists me in using the bathroom. Without these services at night I would be at great risk of illness, injury and death.

Having personal assistance during the day allows me to work, travel to medical appointments and take part fully in the life of my family and community, none of which would be possible without this assistance. As my condition progresses the need for these services will only become more pronounced.

My condition also mandates that I have expensive mobility equipment. This includes a properly fitted wheelchair, customized seating that protects me from pressure wounds and back pain, and that allows me to sit for long periods of time so that I can work, travel and live my life.

All of this costs a lot of money, which is not taken into account in the State's long-term managed care funding formula. As a result, Guildnet is now closing and the State is planning to close my plan, Independence Care System, as well. I believe that these closures represent a failure, not of the plans, but of the State's funding formula.

Back in 2011 when the State moved to require mandatory enrollment into managed care plans for people needing long-term services, individuals with disabilities and disability advocacy groups warned that the proposed funding mechanism did not protect the rights of people who need ten or more hours of personal care each day. It was suggested that a different payment structure was needed for our population and the State was warned that without an appropriate funding structure, plans would cut services for high needs people like me.

What has happened since is twofold. Plans have indeed cut homecare hours without regard for actual need and plans that have not followed this illegal and immoral course have been reduced to financial ruin, as the closure of Guildnet and the imminent closure of Independence Care System illustrate.

What we are now hearing from advocates and attorneys representing the interests of people with disabilities, is that it has become all but impossible for an individual who needs high home care hours to get them authorized. This problem is not going to go away. Depriving high needs people of appropriate home care hours will inevitably lead to injury, illness, death and lawsuits, not to mention the immeasurable loss of productive contributions made by people with high needs who live, work and raise families in New York State.

As the population ages, more and more, not fewer, New Yorkers will need high home care hours. People with disabilities are not going to go away either. We are not going to go back to institutions and we are not going to die without a fight.

The State must address this as the systemic problem it is. As has been said many times, people with high needs, like me and thousands of other New Yorkers, require an appropriate funding structure to ensure that we are able to remain healthy and live in the community, as is our right under local, state and federal law, and the U.S. Supreme Court's ruling in *Olmstead v. L.C.*

Home care has always been the most expensive part of long-term care and it will only get more so. It recently became much more expensive when home care workers gained parity with most other wage laborers after decades of being excluded from the Fair Labor Standards Act. In addition, these workers are covered by the State's recently enacted minimum wage law, as they should be.

The State must take its head out of the sand and create funding streams that actually work for honest, effective, long-term managed care providers and those of us they serve.

Thank you.

Sharifa Abu-Hamda



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From: Andria Berger [REDACTED]
Sent: Friday, December 7, 2018 1:50 PM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment
Attachments: doc20181207124107.pdf

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Please see attachment. Thank you!

Andria Berger
Disability Rights Advocate

[REDACTED]
RCIL
347 West Main Street
Amsterdam, NY 12010

[REDACTED]



12/7/18

Dear Panel Members:

Please accept these comments in response to the request for public input regarding 1115 waivers. The Resource Center for Independent Living is among a network of 39 Independent Living Centers (ILC) across New York, all of which are supported by the Rehabilitation Act of 1973. ILCs provide system change activities as well as individual advocacy services that promote empowerment, independence, and equal opportunities for individuals with disabilities.

Advocates have encountered waiver participants who are without knowledge regarding their rights to individual advocacy services and/or to become involved in ILC system change activities aimed at integration and independence.

CFR 441.555 Support System.

For each service delivery model available, States must provide, or arrange for the provision of, a support system that meets all of the following conditions: (ii) Range and scope of individual choices and options. (xiv) Information about an advocate or advocacy systems available in the State and how an individual can access the advocate or advocacy systems.

Furthermore, Advocates have identified the lack of knowledge also exists among vital providers in the waivers workforce, i.e., Self-Direction Brokers, caregivers, direct support professionals as well as family members and friends who are serving as natural supports to participants.

Therefore, this comment includes a proposal to advance the state in meeting Medicaid program objectives under section 1115 of the Social Security Act.

We respectfully request your consideration to implement policy changes as follows:

- Dedicate a section of the OPWDD Front Door Access to Services handbook to include ILC services and the correlating contact information.
- Implement an ILC informational segment for employees of the Self-Direction program so information pertaining to system change events and activities, as well as individualized advocacy services, can be shared with participants.
- Include the Olmstead Act along with ILC service information onto the Statewide Learning Management System (SLMS) as an annual training for staff who provide direct support services.
- Include ILC service information as part of the state certification process for Family Care providers.
- Include ILC advocacy service information as another avenue afforded to participants who seek out the complaint/grievance or fair hearing process with regards to their services.

Disability Rights Advocates remain committed to supporting Medicaid beneficiaries in receiving individualized, high quality, home and community-based services, thus we appreciate the opportunity to comment in support of the state's great endeavors. Thank you.

Best,
Andria Berger

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From: Jason Lippman [REDACTED]
Sent: Friday, December 7, 2018 4:35 PM
To: doh.sm.1115Waivers
Subject: Comments on New York's 1115 Waiver Programs
Attachments: Coalition Comments - 1115 Waiver 11.29.18.pdf

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To Whom It May Concern,

Please find in the attached file, comments from The Coalition for Behavioral Health on New York's 1115 waiver programs. Please feel free to reach out to me with any questions.

Best regards,

Jason Lippman

Executive Vice President
The Coalition for Behavioral Health, Inc.
123 William Street, Suite 1901
New York, NY 10038

P: [REDACTED]
C: [REDACTED]

www.coalitionny.org

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Downstate Public Comment Day for New York's 1115 Waiver Programs

November 29, 2018

Introduction

Good afternoon state Medicaid Director Donna Frescatore and members of the DSRIP Project Approval and Oversight Panel (PAOP). On behalf of The Coalition for Behavioral Health, I thank you for the opportunity to provide comments for the downstate public comment day for New York's 1115 waiver programs. My name is Jason Lippman, and I am the Executive Vice President at The Coalition for Behavioral Health.

The Coalition is committed to a true partnership with the state as we continue to move forward with the various transformations to the state Medicaid system, including the behavioral health transition to managed care, health care delivery system transformation, including the move to value-based payments (VBP) and efforts to integrate both physical and behavioral health services. Continued system transformation depends on fully utilizing the expertise and strength of behavioral health providers to implement VBP systems, employ data collection practices aligned with behavioral health outcome metrics, address the determinants of health, integrate care and steer enrollment of behavioral Health and Recovery Plan (HARP) members into Home and Community Based Services (HCBS), among other endeavors.

Enable Real Community-Based Partnerships in DSRIP

Performing Provider Systems (PPSs) partnering with community-based providers to avoid hospitalizations is key to a successful DSRIP process. As DSRIP heads into its final phases, community-based providers have yet to realize the benefits of their participation in DSRIP planning. We therefore urge the Performing Provider Systems (PPSs) to use this opportunity to foster meaningful partnerships with community-based providers and allocate funding that has not been fully spent yet to CBOs. In addition, the state should continue to fund CBO planning grants across the state, and unspent DSRIP funds should be allocated to an Innovation Fund available to CBOs and other community-based entities for investment in community-oriented DSRIP-related activities, particularly with relation to pots of dollars intended for workforce sustainability.

Support Community-Based Provider Participation in Value-Based Payments

The transition to VBP must maintain stability for community-based organizations with sound behavioral health performance measures and rates that truly cover the costs of helping people to transform their lives. Providers should be held accountable to metrics that reflect the outcomes we want to attain under DSRIP, VBP and the overall vision of the MRT. That means strengthening communities and empowering people with greater access to health and behavioral health care, where they live and work; and developing real opportunities for true integration of care. People living with severe mental illness and substance use disorders need to be able to access physical health services in the same places where they already receive behavioral health care.

VBP arrangements at Level II or Level III must be held to the requirements that managed care companies contract with at least one CBO and employ at least one intervention to address a social determinant of health. CBOs will need support to enable and foster their

participation in VBP arrangements; the state and VBP lead entities must provide funding to CBOs for technical assistance, contracting for outside expertise, information technology resources and access to timely data to help us get to VBP in a deliberative way.

Medicaid Managed Care

As the state continues to implement its “Care Management for All” initiative to require most Medicaid beneficiaries and services to be in mandatory managed care, it must ensure access to true, meaningful care coordination. Home and Community Based Services (HCBS) are essential in contributing to the wellbeing of people living with behavioral health issues, who are served in managed Health and Recovery Plans (HARPs). Access to HCBS must be made more expeditiously for the people who need them. In addition, special attention must be paid to the transition to Medicaid managed care for children. While enhanced services rates to ease the transition of the children’s behavioral health system will cover the cost of services, they will not offset the expenses incurred by delays to the transition and required health information technology needs. We therefore ask the state to extend the provision of enhanced rates from 6 months to a full year into the children’s transition and provide the system with adequate resources to support it.

Conclusion

To achieve New York's long-term Medicaid redesign goals, community-based behavioral health providers need to be supported with the tools necessary to make these changes, while continuing to deliver high-quality services to the individuals that need them.

I thank you for your time and interest.

Jason Lippman
Executive Vice President
The Coalition of Behavioral Health
123 William Street, Suite 1901
New York, NY 10038



About The Coalition

The Coalition is the umbrella nonprofit, (501)(c)(3), association and public policy advocacy organization of New York’s behavioral health providers, representing nearly 150 non-profit behavioral health agencies. Taken together, these agencies serve more than 500,000 adults and children and deliver the entire continuum of behavioral health care in every neighborhood of a diverse New York City and surrounding areas.

Founded in 1972, the mission of The Coalition is to coordinate the efforts of government and the private sector toward efficient delivery of quality behavioral health services to children, adults and families. The Coalition promotes policies and practices that support the development and provision of community-based housing, treatment, rehabilitation, and support services to all people with mental illness and addictions disorders. Our members serve a diverse group of recipients, including older adults, people who are homeless, those who living with HIV/AIDS and other co-occurring health conditions, violence and other special needs. Coalition members help people with mental health conditions and substance use disorders to recover and lead productive lives in their communities.

The Coalition provides quality learning opportunities, technical assistance and training to staff and leadership of its member agencies and to the professional community on important issues related to rehabilitation and recovery, organizational development, best practices, quality of care, billing and regulations/contract compliance, technology and finance.

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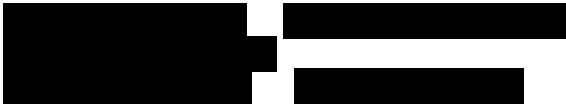
From: Patrick Kwan [REDACTED]
Sent: Friday, December 7, 2018 7:20 PM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment
Attachments: Primary Care Development Corporation - NYS 1115 Waiver Programs Public Forum Comment.pdf

ATTENTION: This email came from an external source. Do not open attachments or click on links from unknown senders or unexpected emails.

Please find attached the Primary Care Development Corporation's 1115 Public Forum Comment. Thank you.

Warmly,

Patrick Kwan
Senior Director of Advocacy and Communications
Primary Care Development Corporation
45 Broadway, Suite 530
New York, NY 10006



The Primary Care Development Corporation (PCDC) is a nationally recognized nonprofit organization and a U.S. Treasury-certified community development financial institution (CDFI) that catalyzes excellence in primary care through strategic community investment, capacity building, and policy initiatives to achieve health equity. Learn more about PCDC's programs to expand and transform the primary care sector at pcdc.org.

December 7, 2018

**New York's 1115 Waiver Programs Public Forum Comment by
the Primary Care Development Corporation**

Thank you for the opportunity to comment on New York's 1115 Waiver programs and issues related to primary care in the recent DSRIP Implementation Update.

The Primary Care Development Corporation (PCDC) is a nonprofit organization and Community Development Financial Institution dedicated to building equity and excellence in primary care. We provide capital financing and capacity building services throughout New York State and across the country. Our mission is to create healthier and more equitable communities by building, expanding, and strengthening the national primary care infrastructure.

Since our founding 25 years ago in 1993, PCDC has worked with over 600 health care sites across New York, including seven Delivery System Reform Incentive Payment (DSRIP) program Performing Provider Systems (PPS) in all corners of the state. Nationally, we have improved primary care access for more than one million patients by leveraging more than \$1 billion to finance over 130 primary care projects. Our strategic community investments have built the capacity to provide 3.5 million medical visits annually, created or preserved more than 10,000 jobs in low-income communities, and transformed 1.8 million square feet of space into fully functioning primary care practices. Through our capacity building programs, PCDC has trained and coached more than 7,000 health workers to deliver superior patient-centered care. We have also assisted more than 450 primary care practices — encompassing some 2,250 providers — to achieve PCMH recognition, impacting care for more than 5 million patients nationwide.

Lack of access to primary care linked to poor health status in New York State. In June, PCDC released our report, [The New York State Primary Care Profile](#), which analyzed proprietary and publicly available data to assess primary care access county-by-county. We identified significant correlations — between primary care access and overall health status; higher poverty rates and worse health outcomes; and rural counties and a lack of primary care access — based on defined measures of access and need. Our recommendations included ensuring a sufficient number of primary care providers in every county, working toward primary care access parity for people living in rural communities, and encouraging capital access and reimbursement models that reward proven quality programs.

Underserved communities have the most pressing need for primary care services, but they are served by dwindling numbers of providers and institutions that lack resources to expand and improve services. Without primary care, families risk costly and serious complications from illnesses that can threaten their long-term well-being and financial security as well as worsen other social and economic inequities.

DSRIP is a crucial opportunity to strengthen and expand primary care, which is central to achieving better health for patients and communities, and lower costs for everyone. PCDC has advocated for a strong and sustained commitment to expanding access to quality primary care throughout the DSRIP program. Primary care must be a central priority in DSRIP – and post-DSRIP - to ensure everyone has access to the critical, cost-effective care and services that help prevent, identify, and treat illnesses before they become more serious, costly, and difficult to treat.

Additionally, as the Department recognized in its *Medicaid Redesign Team Structural Roadmap*, the primary care physician/practitioner “is a pillar in the NYS health care system because they ensure comprehensive, continuous and coordinated primary and preventive care. Good primary care is foundational to optimizing the health of

individuals.” We believe equitable and sustainable reform of the delivery and payment systems depends on primary care.

Primary care funding should be prioritized for the remainder of DSRIP and post-DSRIP. Although primary care is emphasized in DSRIP and the Value-Based Payment Roadmap, the primary care system continues to be underinvested under DSRIP. Primary care is fundamental to the improvements we are seeking in the transformation of the delivery and payment systems. Without a strong and vibrant primary care system that is adequately resourced, technologically enabled, and integrated with other components of the health and behavioral health care systems, the Triple Aim will not be achievable.

While there is a great deal of activity *involving* primary care, we believe that we need to increase the extent to which we are *investing in* primary care.

PPS funds have yet to sufficiently flow to support DSRIP primary care goals. Fund flows and engagement of primary care and other community-based providers have varied by PPS. Overall, according to the [second quarter DY4 PPS update](#), while 45% of total cumulative funds flow dollars (\$941,954,826) went to hospital systems and PPS project management offices, less than 4% of total funds on average have flowed to non-hospital primary care (\$138,266,049), mental health (\$69,559,233), and substance use treatment (\$26,452,915) providers. These figures show that the primary care system — which is already under-resourced — lacks sufficient financial support from the current PPS Funds Flow mechanism. The Department must ensure every PPS is supporting primary care and other community-based providers through timely and adequate fund distribution for the remainder of DSRIP. Only with this support can the primary care system effectively transition to value-based payment (VBP) and sustain the goals of DSRIP in the future state.

Increase in primary care practices achieving NCQA Level 3 recognition should be applauded – as well as appropriately and sustainably supported. Over the last two years, 7,500 providers have achieved NCQA Patient-Centered Medical Home recognition at the highest Level 3. PCDC commends the PPS progress of significantly increasing the number of primary care practices qualifying for NCQA Level 3 recognition, and the increase of 2,500 primary care providers new to NCQA recognition. In addition, we support the Department’s continued investment in practice transformation technical assistance for practices and providers to achieve NYS PCMH.

PCDC also supports the Department’s efforts to promote the PCMH model as a vehicle to move towards integrated care and VBP. Leadership, staff, and providers made extensive commitments to the PCMH practice transformation journey, knowing that there would be incentive payments from the Medicaid program to help support continued sustainability of their often comprehensive redesign, quality improvement, care management, and staffing activities and investments.

Research shows that it takes an average of almost [\\$14,000 per provider FTE](#) to achieve PCMH, and an additional average of more than [\\$8,000 per provider FTE](#) monthly to maintain it. Studies show that the longer a practice has been transformed, the [overall impact of practice transformation](#), particularly the cost savings, is increased.

The Department must ensure funding and investments in primary care providers during the remainder of DSRIP as well as through other current and future programs to assure that they can sustain patient-centered models of care.

The administrative burden on primary care providers should be alleviated. As a result of the numerous NYS health insurance plan along with the additional payer arrangements, including Independent Practice Associations (IPAs) and Accountable Care Organizations (ACOs) as well as DSRIP and Health Homes, the administrative burden on large and small primary care practices has become increasingly complex and burdensome. Under the current NYS



system, primary care providers are often contracted with several managed care organizations (MCOs) for commercial as well as Medicaid and Medicare, in addition to serving some patients with Medicaid and/or Medicare fee-for-service coverage. This, in addition to the significant overlap of providers being part of more than one PPS and several Health Homes, creates enormous complexity and administrative burden for providers. As NYS continues to reduce silos and work towards high performing networks, a critical focus should be on leveraging this process to identify streamlined approaches to reporting, billing, and contracting that support providers who are engaged with multiple actors within the system.

The health system transformation sought by New York State through the 1115 waiver can only be accomplished with sufficient, quality primary care that is accessible to all families and communities. With overwhelming evidence of its positive impact on improving health care quality and outcomes while lowering health care costs, primary care is the most reliable means of ensuring patient and community health. We are optimistic about the commitment New York State has made to primary care. We also recognize the need more investment and more effective policies to achieve the promise of primary care.

We look forward to working with the Department and the many other stakeholders who share our concerns and our vision in the next stage of evolution of health care reform in New York State.

Contact:

Primary Care Development Corporation (PCDC)

Avital Havusha, Managing Director of Performance Improvement

Office: [REDACTED] | Email: [REDACTED]

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doh.sm.1115Waivers

From: Civics League for Disability Rights [REDACTED]
Sent: Friday, December 7, 2018 7:36 PM
To: doh.sm.1115Waivers
Subject: 1115 Public Forum Comment
Attachments: Mahmud_Iffat_Testimony_2018.docx; Trocchia_Anthony_Testimony_2018.doc

ATTENTION: This email came from an external source. Do not open attachments or click on links from unknown senders or unexpected emails.

Greetings,

Please find attached testimonies from 2 members of the Civics League for Disability Rights.


Thank you,

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Warm regards,

Sharifa Abu-Hamda
Civics League for Disability Rights





November 29, 2018

TO: DOH's Medicaid Redesign Team (MRT) - 1115 Waiver Program

RE: IMPACT: Long-Term Managed Care Organization- ICS (Independence Care System)

My name is Iffat Mahmud-Khan. I am a person who has a permanent disability that requires use of a motorized wheelchair for mobility purposes and have several other ailments. I rely on the services provided by the managed long-term care organization, Independence Care System (ICS), which has supported my healthcare and mobility needs for the past 13 years, but now it is in danger of closing. Why?

Why is it that the disabled population is the last group to be thought about or even considered, when funding allocations are discussed and decided upon? Children have access to community programs such as “Mommy and Me”, after-school programs and services, as well as local community centers for socialization and recreational activities. The elderly population has access to companion services, Meals on Wheels, senior centers that provide daily meals as well as socialization and recreational activities. The services these populations receive are absolutely beneficial and offer enrichment as well as fulfill a need in the community.

So, why is it that people with disabilities are still not considered to be valuable enough members of the community when it pertains to our need for living independently? This includes the need for quality healthcare and support services with respect to traditional homecare such as Home Health Aides, Personal Assistants under Consumer Directed Personal Assistance services, not to mention that these workers deserve a decent living wage for all the care and concern they provide on a daily basis.

ICS fills that gap for people with physical disabilities. It offers community-based services (such as healthcare and personal care services) to over 6,000 people with physical disabilities, who live within four of the five boroughs throughout New York City. ICS is unique, based on the fact that this organization is the only one of its kind. In addition, ICS also offers service providers, who deliver as well as assist with repairs and/or replacement of assistive devices, including mobility aides, motorized and manual wheelchairs, and durable medical equipment just to name a few examples. These supports are what assist people with disabilities to maintain their quality of life at home and in their communities. Furthermore, the people who work at ICS really have a vested interest in the members they serve and support.

As a current member, ICS is an integral part of my life. I am extremely grateful that ICS is in existence. They assist me with living my life in my own home and within my own community as independently as possible. Most of the people who work there can attest to how much I appreciate the services and activities that are offered. One person I have been very fortunate in getting to know and have had the privilege of working with is Ms. Ana Nunez, who has been my care manager and social worker for over ten years. With her support, we have developed a long-lasting relationship of trust and understanding over the years. She has been the best advocate on my behalf pertaining to my needs for homecare services, medical appointments, medical supplies and following up on things related to the mobility devices I use. She is also compassionate, caring and concerned for me. I have truly appreciated her sincere interest in how I am doing as a person. What I respect the most about Ms. Nunez is her ability to listen and the fact that she really hears what I’m saying. Listening and hearing are two rare traits in a person, but she has them both. She is truly unique in her style, which is truly a breath of fresh air.

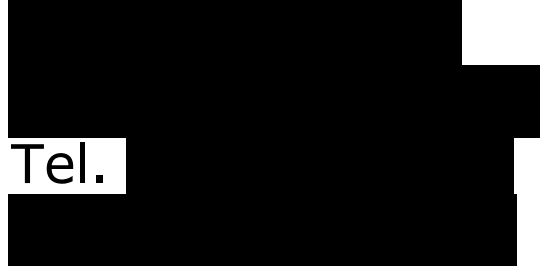
If organizations like ICS no longer exist to assist people with physical disabilities, moments of feeling inadequate, invisible and helpless will only increase. The impact of ICS closing would be an immense burden on me, my family as well as all the other thousands of people with physical disabilities in New York City. If anything, ICS should be expanding to all five boroughs, not closing down. Or is it that people with physical disabilities represent a burden to society? Are we half-people, because we are not considered physically “normal” enough? Are there not enough of us to care?

I refuse to believe any of that is true, and I have no idea where I will go if ICS closes its doors. Unfortunately, there is no other place that will provide the same level of services and resources as ICS. While the Visiting Nurse Service of New York (VNSNY) is on the table as an alternative option, it’s for-profit and primarily focused on healthcare. The bottom dollar will always come before quality of service and the quality of life of its clients. ICS focuses on the needs of people first and finds a way with its resources to make sure its clients live the best full life they can. Maintaining ICS is so important and vital for people with physical disabilities and to take it away is like severing our lifeline – independence and living our lives with integrity.

I appreciate your time, attention and consideration.

Sincerely,
Iffat Mahmud-Khan

Anthony Trocchia



I must begin by saying: Managed Long-Term Care providers are not interchangeable. My name is Anthony and I am a disabled individual who receives vital personal assistance service from New York's largest and oldest Consumer-Directed Personal Assistance Program.

When I learned in 2012, that I was mandated to join a MLTC, it was a no-brainer that I would choose Independence Care System (ICS). ICS had been around since the early 2000s and I knew many people who were clients and quite satisfied.

Upon joining, I liked that ICS would respect each member's desire for autonomy. I explained to my Care Manager that I preferred to be contacted monthly via email. I did not need or want phone calls checking in on me. If I needed something, I would

contact ICS. Unlike many MLTCs who have a majority of clients who are elderly, ICS was developed around the needs of people who are physically disabled, many from birth.

That is me. I was born in 1969 with a neuromuscular disease called Spinal Muscular Atrophy Type III. I know no other kind of life. My psychology is that of a lifelong person with a disability who has had to fight for a place in this society.

So far, ICS has truly been great. ICS has not ever attempted to take over my life.

Earlier this year, I began hearing that ICS was having financial problems. It was due to the capitation rate MLTCs use. People like me, who require 2 12-hour shifts, 7 days per week cost more than the state gives ICS per individual.

The capitation rate basically turns clients into cash machines. In order for a MLTC to stay afloat, it needs to recruit as many people as possible who need the least amount of home care hours. Thus, in 2012, recruiters could be seen around the city offering trivial incentives for people to join various plans.

I kept asking myself, who is on this MRT that makes such vital decisions affecting my life. I looked online and realized that the MRT is made up of approx 32 people, the vast majority of whom are service providers. I found it shameful that, though home care and personal assistance service consumes a large chunk of the Medicaid budget, no home care clients or consumers were on the MRT. The time is now upon us, as it inevitably would be, for the MRT to create a pay structure for high-needs individuals. This issue will not magically resolve itself. It must be dealt with.

ICS is a terrific agency. How often do you hear beneficiaries praising a government program? People are happy with ICS and their approach is unparalleled in the world of MLTCs.

People like me who need a high volume of hours will not go away. We will cost the same no matter which MLTC we're with. The reality is we are fighting for our lives. We want to live in the community and make the decisions so many non-disabled people unconsciously take for granted.

Please create a new pay structure that reimburses MLTCs for high-needs cases. If you were on the receiving end of services, you would want ICS to be there for you or someone you love.

I applaud the State of New York for its commitment to home-based long-term care, unlike the majority of the states in the U.S. that have an institutional bias.

Understandably, New York's Medicaid Redesign effort is a constant work in progress. We learn and grow. As the state motto, Excelsior, expresses, Ever upward!

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November 29, 2018

Public Hearing -Medicaid Redesign Team on 1115 Waiver Program

My name is Mary Somoza and I am the mother of four adult children including my 34-year-old twin daughters Alba and Anastasia. Both of my twins are quadriplegic, with significant spasticity due to their cerebral palsy. They cannot walk, sit up in bed, turn in bed, transfer from bed to their wheelchairs, or bath seat, dress themselves, feed themselves (Alba has a gastronomy feeding tube) or do any of the things most of us here today do without thinking. They depend on home care assistance 24/7.

Nonetheless, they both lead meaningful lives in the community, working part time and paying taxes. They can only work part time as if their income goes up, they lose the benefits that keep them out of institutions or nursing homes. That includes their homecare.

I also came here to support the many participants from ICS who are now in danger of losing their 24-hour coverage, losing the support system provided by ICS, that also keeps them in the community, with a quality of life, and common sense supports such as the wheelchair clinic on site. As all people who depend on wheelchairs know, if your chair is not working, your quality of live comes to a standstill. ICS knows that, and provided quality services to the individuals they serve, and because of that, they are now at risk of closing because the Department of Health did not calculate appropriate rates for high need cases, most of whom flocked to ICS as other plans would not accept their level of care and hours.

Many of the people at ICS are our friends, advocates who have made many things possible that my twin daughters benefit from today. Many are now aging, dependent on ventilators, and experiencing not only the difficulties of their disabilities, but of the health consequences of getting older. They should never have to go through the anxiety that they are now feeling, and

if they will eventually end up in a nursing home, which incidentally costs the state far more than supporting people with disabilities, so they can live at home.

My daughters have a developmental disability, and now, OPWDD and the state are pushing us, at break-neck speed, into managed care. Despite all the euphemisms about better health outcomes, we all know that the real reason is to save money – and that means cutting services. OPWDD and the DOH are on a fast track to put the most vulnerable population into a system that will invariably diminish the quality of life of our family members.

I am a Governor Appointed member of the Office of People with Developmental Disabilities Commissioners Advisory Council appointed by every Governor since 1991. I have seen such a tremendous lack of transparency coming out of this whole stealth operation to put our family members under the control of CCO's (a disaster happening as we speak) and eventually managed care. Parents are terrified, as many of us are aging, and wondering what will happen when for-profit entities decide what level of care our children and young adults will have when we are no longer around to advocate for them.

I don't ask you to take my word for this, but there are two reports which should be mandatory reading for everyone involved in this mis-guided endeavor. I will give a copy of each with this testimony. Stakeholders like us – every family member who has a child/adult child with a developmental disability have not been brought into the decision-making process, we have not been informed of where we are in the process until it is "too late", and we simply find ourselves overwhelmed with the speed at which this is occurring.

We look at what is happening to ICS, and Guildnet, both who are now bankrupt because they provided care to the highest need's individuals with disabilities, and we are seeing the writing on the wall of where this is all going. You will overwhelm family members who have dedicated their lives to keeping their children in the community, and many of them will give up, and surrender to the nursing home industry. Is that what you want?

I ask you to reconsider the track the state is on right now, and think about that infamous word, Willowbrook. Remember what happened there when you make decisions. In the age we live in, it could still happen. Please do not let that happen.

Respectfully submitted,

Mary Somoza



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)

October 3, 2018

Disability Rights New York (“DRNY”) submits the following comments on the Department of Health (“DOH”) and the Office for People with Developmental Disabilities (“OPWDD”) proposal: 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) (“Plan”). As the statewide Protection and Advocacy system for people with disabilities, DRNY has an interest in ensuring that people with disabilities receive the support they need to live independently in their communities. We appreciate DOH and OPWDD’s commitment to these goals. However, the current plan for a successful transition to managed care is grossly deficient.

I. Plan Development

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

As noted in DRNY’s previous comments, under Title II of the Americans with Disabilities Act, OPWDD and DOH are required to take steps to ensure their communications with people with disabilities are as effective as communications with people who do not have disabilities.¹ However, the 92-page highly technical Plan is neither clear nor an effective means of communication for people with intellectual and/or developmental disabilities. The length, coupled with the format, makes the Plan inaccessible.

The 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 are unaware of the magnitude of changes to come. They are therefore unable to meaningfully understand the transition to managed care.

¹ 28 C.F.R. §35.160 (2005).

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Lack of Stakeholder Participation

The Centers for Medicare and Medicaid Services (“CMS”) requires States to solicit and engage with stakeholders in the development of an 1115 Waiver, including the Plan.² These outreach efforts must also include a summary of the Plan, which neither DOH nor OPWDD has provided to the public.³ Further, the State is required to convene at least two public hearings on the Plan. While OPWDD held public hearings on the transition to Care Coordination, to date it has not convened public hearings solely on the transition to managed care. Accordingly, DOH and OPWDD have failed to meet their obligations as required by CMS, and therefore this Plan must be retracted until they do so.

In addition, OPWDD and DOH claim that the plan to discontinue the Home and Community Based Services (“HCBS”) Waiver and transition to managed care is an outgrowth of specific recommendations made by OPWDD’s Transformation Panel. However, of the 18 members of the Transformation Panel, only two are parents of individuals with developmental disabilities and only one is a self-advocate and direct stakeholder. Representation by recipients of services through OPWDD is shockingly inadequate. Similarly, representatives of self-advocacy and disability rights organizations, as well as any other organizations or agencies that represent the rights and interests of people with disabilities must be involved in this process. Excluding these voices compromises effective transition and the possible implementation of managed care.

The Plan is Incomplete

As noted in DRNY’s prior comments, the Plan offers grossly inadequate specificity regarding implementation of managed care. The Plan itself states that the final transition to managed care “will be described in amendments to the Comprehensive HCBS Waiver and the MRT 1115 Waiver.”⁴ DOH and OPWDD’s piecemeal approach compromises an effective assessment and response. Instead, a comprehensive managed care proposal should be released, rather than the current fragmented approach.

No Translated Versions of the Plan

As noted in DRNY’s prior comments, the lack of readily available translated versions of this important document prevents a significant percentage of service recipients and their families from commenting.

² 42 CFR § 431.408

³ Id.

⁴ Plan, 5.

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There is no translation of the Plan in Spanish or other languages spoken by service recipients and their families. According to the 2015 census, 15.2% of New Yorkers speak Spanish. By failing to provide a translated plan, DOH and OPWDD are excluding a large population of service recipients and their families. Further, it is unclear whether a request for a translated document is even possible or how such a request can be made. Even if such a request can be made for translated documents (as DOH has stated previously in this process) that stance erroneously assumes someone with Limited English Proficiency (“LEP”) will not face barriers in navigating such a request process. With such a tight timeline set for review and comment LEP persons are not likely to be able to request the translation, receive it, read it, comprehend it, and be able to provide comments before the deadline.

Lastly, there is also a lack of linguistic competence as this Plan is not provided in any language other than English. According to the 2015 NYS census information, 30.9% of New Yorkers are categorized as “Other” language speakers in the home. DOH and OPWDD should have translated versions of the plans for public comment readily available in the most common five languages spoken in New York State to ensure LEP participation.

II. Comments on the Substance of the Plan

Existing Shortage of Services and Workers is Not Addressed

Despite prior comments, the Plan continues to be entirely silent as to how the proposed transition to managed care will address the current scarcity of direct support professionals (“DSPs”) to deliver services to individuals with intellectual and/or developmental disabilities. DRNY has received numerous complaints from individuals who are eligible for HCBS Waiver services, but cannot obtain services due to a dearth of DSPs.

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. Some individuals without complex needs are forced to go without any community services despite being approved for them. For example, DRNY has received complaints that numerous persons approved for HCBS Waiver services such as respite, community habilitation, supported employment, and day program will oftentimes be eligible for these services for years, but not actually receive them because of systemic issues within the OPWDD service delivery system. Many times the only solution is for individuals and their families to self-direct them. However, many individuals and their families are unable to find workers and coordinate these services on their own, and thus go without any services.

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The Plan is silent as to how managed care will specifically be able to address this issue. Since managed care organizations (“MCO”) will eventually receive a capitated rate, in time this problem will likely be exacerbated, as this model will incentivize MCOs to deliver fewer services to individuals with intellectual and/or developmental disabilities. In fact, it is DRNY’s understanding that an MCO has no incentive to keep individuals with complex medical needs out of nursing homes or other institutional settings; once the placement occurs the individuals will be removed from an MCO’s plan after 90 days. Before any move to managed care is implemented, OPWDD and DOH must formally and thoroughly assess the existing gaps in the service delivery system under Medicaid fee-for-service (“FFS”), and ensure that a managed care model does not continue or exacerbate this issue and the institutionalization that results.

Financial Concerns of MCOs

The Plan raises concerns regarding the long-term financial viability of the capitated-rate managed care model as well as the incentive for MCOs to profit by providing fewer services to members. As we have seen in the similarly-organized managed long term care (“MLTC”) system, multiple MLTC plans have closed or are in danger of closing due to financial issues, leading to disruption in member care.

The Plan states that at first OPWDD HCBS Waiver services and OPWDD residential services will be paid via an FFS rate pass-through, while the remainder of the benefit package is paid via a capitated rate. Then, 24 months after the implementation of mandated managed care, OPWDD HCBS Waiver services and OPWDD residential services will be placed into the capitated rate. This means that individuals with intellectual and/or developmental disabilities who have complex and intense medical or behavioral needs will be given the same funding levels as other individuals who have significantly fewer needs.

The Plan lacks any details regarding how capitated rates will be set for the SIPs-PL other than to say that they will be “actuarially sound.” It is disturbing 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, it will only further exacerbate the availability of DSPs and workers.

Even under the current system, individuals with the most complex needs are denied 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 lingering in institutional settings despite enhanced funding. Consequently, if OPWDD and DOH eliminate enhanced funding for these and other individuals with complex needs, there is no doubt the number of people unable to

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access community based services will only grow, as will the number requiring institutionalization.

Accordingly, the Plan must directly require DOH and OPWDD to set the capitated rate 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.

DOH and OPWDD should also consider providing start-up funding for the development of SIPs-PL, but any such funding should be fully publicized and transparent.

Medical Necessity and Utilization Management Concerns

As in the broader New York managed care system, SIPs-PL are required to use New York's "medical necessity" standard for utilization management ("UM").⁵ DRNY is concerned about the use of a medical model to assess the need for non-medical services like HCBS. While we appreciate that, per the Plan, "the State supports a person-centered approach to care in which the individual's needs, preferences, and strengths are considered in the development of the Life Plan,"⁶ the Plan needs to include concrete detail on how this will be defined, carried out, and enforced.

For example, the Plan needs to detail the protocol for the SIPs-PL to "review and approv[e] of Life Plans inclusive of HCBS Waiver services."⁷ If a CCO/Health Home or other care manager develops an appropriate Life Plan, by what standards and processes can the SIP-PL overrule the drafter? Again, a capitated-rate model does not encourage MCOs to approve full and comprehensive services. A denial by the SIP-PL of a Life Plan service should trigger notice and due process rights.

Further, the Plan states that "When 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."⁸ We support this proactive approach. However, the State should develop a specific protocol so that parties can understand the responsibilities of the SIP-PL in this situation and hold the SIP-PL accountable if it fails to meet

⁵ Plan, 36.

⁶ *Id.*

⁷ Plan, 37.

⁸ *Id.* at 36.

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its responsibilities. Clarity is also needed regarding how this approach coordinates with the formal appeals process to ensure non-interference with due process rights.

Finally, in addition to the UM protocols being approved by the State, they should also be standardized and public.

Lack of Due Process Protections

The Plan lacks sufficient detail on due process protections, particularly because SIPs-PL are new to the responsibilities of an MCO in New York State. The Plan fails to discuss the process for appealing an adverse decision, initiating an objection, or requesting a Medicaid fair hearing.

The Plan states that SIPs-PL “must meet[] all requirements in the MMC Model Contract unless otherwise stated.”⁹ We understand that to include the Model Contract’s provisions and requirements pertaining to the grievance, appeal, and fair hearing process. However, due to the critical importance of due process rights, particularly in this transition period, we urge DOH and OPWDD to detail the due process rights in the final plan, rather than incorporating them by reference to the Model Contract.

Further detail is especially important because the due process provisions of the MMC Model Contract/managed care system are different from those in the OPWDD system. Presently, 14 NYCRR § 633.12 provides individuals in the OPWDD system 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). This objection process does not require the individual to exhaust administrative remedies. Given the nature of the services at stake – including living arrangements and critical community supports – the protections in § 633.12 must be incorporated in this Plan.

The Plan should also be clear that due process protections apply to dis-enrollments. Again, it does seem that the MMC Model Contract rules on disenrollment in Section 8 and Appendices H and Q will apply. Nevertheless, we believe that as these disability-focused SIPs-PL are developed, it should be emphasized that, per the Model Contract, they may not dis-enroll a member “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 the Enrollee’s special needs.”¹⁰

⁹ *Id.* at 19.

¹⁰ 42 C.F.R. § 438.56.

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Likewise, DOH, OPWDD, Local Departments of Social Services (“LDSS”), and the SIP-PLs should be prepared to coordinate and solve issues of Medicaid eligibility to ensure that members do not lose access to services. This should include, where appropriate, communicating with members, assisting with recertification, and providing a grace period of managed care coverage. This has been a recurring issue across the managed care system and we hope that the OPWDD transition can learn from past mistakes.

Failure to Discuss Ombudsman

The Plan does not mention the managed care participant ombudsman. DOH and OPWDD must provide specificity regarding the ombudsman and require that the new MCOs cooperate with the ombudsman. The Plan must include language similar to the MLTC Model Contract on this topic (“The Contractor will cooperate with, and may not inhibit, the Participant Ombudsman in the exercise of its duties . . .”).¹¹ In addition, we recommend that each SIP-PL be required to name a designated contact person to respond to concerns and questions from the ombudsman.

Care Coordination for Individuals who are Dually Eligible

The Plan requires a clear definition of “coordinat[ing] the benefit package with Medicare”¹² and the responsibilities of the SIPs-PL and care managers for arranging for Medicare-covered services for their dual-eligible members, such as durable medical equipment (“DME”).

We have seen in the MLTC system that MLTC care managers do not fully understand or implement coordination of Medicare services, particularly in regards to DME, leading to long wait periods and missed opportunities for needed equipment and supplies.

The Draft Plan Lacks Meaningful Information about the Coordinated Assessment System

The Plan includes very little information on the Coordinated Assessment System (“CAS”). In the definitions section, it describes the CAS as “an assessment tool specifically tailored to capture the unique health and support needs of individuals with I/DD in New York State . . . [that] is being implemented in phases.”¹³ The only other mention of the CAS is in Attachment D, outlining the training topics to be completed 30 days before the new system goes live.

¹¹ MLTC Model Contract Article V(E)(6) on Enrollee Protections.

¹² Plan, 9-10.

¹³ *Id.* at 12.

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Other than these meager references, the Plan contains no information on the CAS or what role it will play within the SIPs-PL. For example, it does not state whether the CAS will be used as an eligibility screening tool as is now the case with standardized assessment tools for some other HCBS programs or whether and how it will impact the amount or type of services that an individual is able to access. The 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. Nor is there any explanation of the timeline for implementation of the CAS statewide or where or when the aforementioned phases will be occurring.

This lack of information prevents stakeholders from providing informed feedback on the role of the CAS in the SIPs-PL structure. Previous feedback from individuals, families, and other stakeholders demonstrates that the CAS is not well understood, particularly how it works and how it impacts the services that a recipient is able to receive. OPWDD and DOH should provide additional information about the CAS and fully detail how CAS results will be used by the SIPs-PL. This information should be released as early as possible to afford stakeholders sufficient opportunity to comprehend this component of the new system and offer feedback to shape future iterations of the plan.

HCBS Services in Rural Communities

The Plan states each MCO will contract with at least two HCBS provider agencies to deliver HCBS services in each county. However, in many rural counties there is only one service provider who offers in-home supports and services like respite and community habilitation. Moreover, according to OPWDD's provider directory there is presently not a single voluntary agency that offers these in-home services in Hamilton County.

The Plan states that in counties like these where there is insufficient network capacity an MCO must contract with a provider in a neighboring county. If network capacity is still insufficient then the MCO should contract with a provider in another Developmental Disabilities Regional Office ("DDRO"). The Plan gives the example that if someone lives in Rensselaer County and cannot obtain an HCBS service from a provider within its DDRO region, the MCO should just contract with a provider in Sunmount or Hudson Valley to provide the HCBS service. This proposal is wholly impractical. It is unreasonable to assume that a DSP would be willing and able to drive two or three hours each way, unpaid, to deliver in-home respite to someone in a neighboring county or region. Before the transition to managed care occurs, OPWDD and DOH must increase service delivery capacity and ensure that each county has at least two providers that can deliver HCBS services.

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Health Services in Rural Communities

The Plan states that individuals will be allowed to continue with their medical providers for 24 months following enrollment for episodes of care that were ongoing during the transition. After this period they will be required to obtain medical and behavioral care from in-network providers of their MCO. In rural communities this change could cause significant disruption in the ability of individuals with intellectual and/or developmental disabilities to obtain needed medical and behavioral services.

Rural communities already have significant health service gaps including severe shortages of physicians and specialists that require residents to utilize tertiary medical providers.¹⁴ These difficulties will make it challenging for an MCO to construct a provider network in rural areas, as MCOs “can threaten rural health delivery systems with selective contracting that omits local providers.”¹⁵ Accordingly, when Vermont constructed a managed care system it required MCOs to contract with any willing medical provider who could meet the plan’s contract terms, thus ensuring access to medical services in rural communities.¹⁶ The Plan does not include this needed provision for rural communities and should be amended accordingly.

Out-of-State Call Centers

The Plan states that call centers can be placed out-of-state so long as customer service representatives are “adequately trained on all New York State requirements.”¹⁷ However, the Plan makes no mention of what “adequately trained” means and how DOH or OPWDD will implement and ensure such a threshold is met.

It is very concerning that call centers, especially crisis call centers, will be based out-of-state. Call centers have immediate and critical interactions with service recipients and families, yet DOH and OPWDD appear willing to abdicate needed oversight and training requirements. Call centers must remain under the watchful eye of DOH, OPWDD, and other stakeholders. If DOH and OPWDD mistakenly move forward with out-of-state call centers and employees, it should be made clear to service recipients and stakeholders how these individuals will be trained to ensure they have the appropriate knowledge of New York State’s complicated service system, particularly when an individual is in crisis.

¹⁴ Eileen Griffin and Andrew Coburn, Integrated Care Management in Rural Communities, 12, (May, 2014), accessible at: <https://muskie.usm.maine.edu/Publications/rural/Integrated-Care-Rural-WorkingPaper.pdf>.

¹⁵ Id.

¹⁶ 8 V.S.A. § 4089b (2015).

¹⁷ Plan, 28.

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Further, Attachment C of this plan states the following positions in the Plan are *not* required to be based in New York State: ID/DD Dental Coordinator, ID/DD Utilization Management Director, Member Services Director, Quality Management Director, Information Systems Director, Utilization Management, Clinical Peer Reviewers (multiple persons), Quality Management Specialists (multiple positions), and Provider Relations (multiple positions, and states “some staff must be in New York State”). Thus, out of 19 positions listed nine are not required to be in state. Three of these positions, (Clinical Peer Reviewers; Quality Management Specialists; Provider Relations) will also include multiple employees in each of these categories. Out of 10 Managerial Positions, four may be located out-of-state. Out of four categories of Operational Staff, four may wholly or partially be out-of-state. There is no clear reasoning stated in the Plan why these positions are permitted to be located remotely and how DOH will ensure these persons are trained and will adequately understand the complicated Medicaid system now implemented in New York State, let alone local resources and challenges. Finally, DOH and OPWDD should make clear what checks and balances are being put in place to oversee quality control when utilizing an out-of-state call center and employees.

Self-Direction

The Plan states that under managed care the “[u]tilization management protocols for self-direction will follow State guidelines and budgeting standards.”¹⁸ DRNY has received several complaints that current budgeting levels for self-direction are inadequate for individuals to live in the community. Presently, individuals with complex behavioral, medical, or mobility needs are often unable to participate in self-directed services because of OPWDD’s cap on reimbursement. Accordingly, individuals who would like to move out of a more restrictive setting are unable to do so. OPWDD and DOH should remove or reassess budget caps so long as someone’s budget is cost neutral.

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

Despite repeated inquiries, the Plan remains entirely unclear what the future role of OPWDD’s DDRO and the Developmental Disabilities Services Offices (“DDSO”) will be when managed care is mandated. While the Plan states that the DRRO and DDSO will continue to operate under managed care, it is silent as to what this will actually look like. 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. Finally, the Plan is silent as to what the role of the DDRO’s Front Door will be when managed care is implemented.

¹⁸ Plan, 36.

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The Plan is also silent as to the role of the DDSO under managed care. It is unlikely that an MCO would want to contract with the DDSO for these services as they are often more expensive because DDSO employees are paid a much higher rate than those operated by voluntary agencies.

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 often provides 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.

Transitional Care Planning for Residential School Students

As noted in DRNY's prior comments, the Plan states that MCOs will provide discharge planning for residential school students. However, it is entirely unclear from the Plan how MCOs will be positioned to conduct discharge planning for residential school students.

Currently, OPWDD provides transitional funding for these individuals until a discharge plan can be developed. From the Plan it is unclear if OPWDD and DOH would now delegate this responsibility to an MCO. In addition, OPWDD provides enhanced funding for these individuals to provide a much-needed incentive to service providers to provide community services. However, according to the Plan this enhanced funding would be discontinued in 2024. Consequently, the Plan fails to specify how transitional and enhanced funding will operate under managed care. Finally, OPWDD's DDROs employ individuals whose job it is to coordinate the discharge of young adults in residential school. The Plan is silent as to whether these DDRO representatives will continue and, if so, how they will interface with an MCO. If OPWDD intends to privatize these DDRO positions it should explicitly state so.

Lack of Clarity Regarding the Future of State-Funded Services

The Plan states that "when an individual is institutionalized or in an unauthorized setting the individual will not receive HCBS."¹⁹ However, as noted in DRNY's prior comments, OPWDD currently 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

¹⁹ Plan, 43.

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during school breaks and holidays to ensure necessary care. In addition, individuals in rehabilitation settings, hospitals, or skilled nursing facilities often require environmental modifications (“EMODs”) made to the community setting as a condition of safe discharge. Currently, it is necessary for these individuals to obtain these EMODs through State funding. The Plan is silent as to whether State-paid services will continue under managed care. OPWDD and DOH should clarify if State-paid services will continue and, if so, how they will be obtained and funded.

No Specifics Regarding Family Supports and Services

The Plan is silent as to whether individuals and their families will continue to be eligible for family supports and services. As noted in DRNY’s previous comments, family supports and services provides necessary funding for a variety of services. OPWDD and DOH must clarify if family supports and services will continue and, if so, how families will obtain these funds.

Failure to Address Individuals in Children’s Residential Projects

As stated in DRNY’s previous comments, the Plan as written is silent as to whether Children’s Residential Projects (“CRP”), as jointly funded programs between New York State Education Department and OPWDD, will be incorporated into managed care. DOH and OPWDD should provide clarity on this issue as CRPs serve a critical need for students with disabilities.

Failure to Address START Services

As discussed in DRNY’s prior comments, the Plan states that MCOs will enter into contracts with regional Systemic, Therapeutic Assessment, Resources, and Treatment (“START”) programs so individuals can obtain crisis services when needed. The Plan once again fails to address START’s systemic problems and how it will reduce institutionalization by providing adequate crisis intervention services to individuals with intellectual and/or developmental disabilities.

Based on DRNY’s experience with individuals involved with START services, the State lacks tangible services to adequately address individuals in crisis. For instance, almost all OPWDD regions lack a freestanding crisis respite program to treat and evaluate individuals with complex behavioral needs. Some regions do not have START; others have long waiting lists. The Plan must address improving the inadequate infrastructure critical to START’s purpose and success.

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Failure to Address Ability to Access LDSS Prevention Services through Managed Care

As discussed in DRNY’s prior comments, it is not clear whether individuals will still be eligible for services from their LDSS once managed care is implemented. The loss of LDSS services, including preventive services, family abuse prevention, budgeting assistance, and child care assistance would be detrimental to many families and individuals. Without the ability to access these services, many children with disabilities could be unnecessarily placed in institutional settings through the foster care system. The Plan must clarify whether access to these integral services are still available under managed care.

Failure to Address Access to Skilled Nursing and CDPAP through Managed Care

As noted in DRNY’s prior comments, the Plan is silent as to whether individuals will continue to be eligible for consumer directed personal assistance program (“CDPAP”) and skilled home nursing services. Without these supports, individuals would require institutionalization in nursing homes and similar facilities. Because of the OPWDD cap on the self-direction budgets, supplementing with CDPAP and skilled nursing is critical to community-based living for individuals who require close to 24/7 support in their homes. The Plan must specifically allow continued access to supplemental services.

Social Transportation

The Plan states that managed care will add social transportation as a service. We fully support this. However, the Plan fails to specify how an individual will access this service as it is not currently offered as an HCBS service to individuals with intellectual and/or developmental disabilities. The Plan should provide more details regarding the mechanics of this new service.

III. Conclusion

When managed care was implemented in Kansas, the results were detrimental to 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.”²⁰ Services were cut substantially at the sole discretion of managed care companies.²¹ In addition, Wisconsin also experienced significant problems when managed care for people with intellectual and

²⁰ 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>

²¹ *Id.*

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developmental disabilities was implemented there when three MCOs became bankrupt and three others were forced to consolidate due to financial issues.²²

While the 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 will result in lack of access to community based services and increased institutionalization of individuals with complex needs.

As written, DOH and OPWDD should not implement this Plan, as it will have profound negative effects on individuals with intellectual and developmental disabilities. OPWDD and DOH must conduct further outreach to stakeholders, and provide clarification, measurable outcomes, and further development of its proposal to ensure access to necessary services for people with intellectual and developmental disabilities. As we have stated before, as the federally mandated Protection and Advocacy system in New York State for persons with disabilities, DRNY would welcome the opportunity to participate in this process.

²² Telephone Interview with Disability Rights Wisconsin (August 10, 2017).

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Statement for New York's 1115 Waiver Programs Public Comment Day

My name is Emily Rogan and I am Health & Welfare Council of Long Island's Manager for Health Equity. Thank you for the opportunity to speak today on behalf of Health Equity Alliance of Long Island-known as HEALI-a coalition of over 80 health & human service agencies representing our entire region-from Montauk to Elmont.

For over 70 years, the Health & Welfare Council of Long Island has been supporting communities through direct service and advocacy & policy work and by convening our membership of nearly 200 non-profit agencies across the region.

We are grateful for the funding from the NYSDOH CBO planning grant. It has enabled us to assess the infrastructure of the non-profit sector on Long Island and work with our partners to develop a strategic plan to connect health & human service agencies in our region, through improved technology and shared data. In addition, we've been examining how services are delivered to clients throughout the region and where improvements can be made.

Since beginning this work, we've identified three key areas which the state can impact:

1. As we look at integrating services and data sharing on Long Island, we believe that departmental data and reporting systems at the state level need also be integrated and improved. For example, a high-needs child with food insecurity might appear in three separate state systems:
 - WIC-Dept of Health
 - SNAP-Office of Temporary & Disability Assistance
 - School Meals Program-Dept of Education

Three funding streams. Three systems. No communication or integration between them to serve this child. We believe that systems change must happen at ALL levels in order to better serve people.

2. Managed Care Organizations, healthcare providers and Community Based Organizations all tell us there is a significant gap and tremendous need for care coordination and navigation of client services. We know that clients are overwhelmed by the complexity and disconnect within the human services sector alone. They find themselves visiting multiple sites, completing redundant intake forms and rushing from location to location in a region desperately lacking adequate transportation systems. Clients experience parallel challenges within the medical sector and as a result, referrals are dropped and appointments are missed. The system as it stands is not designed to help people get the comprehensive care they need and deserve.

CBOs are uniquely positioned to fill that gap; we know our clients and communities and we have the expertise to put a community care model in place. The planning grant has provided the financial support to identify an appropriate model and develop a business plan, however, implementation funding from the state would enable us to put that plan into action and develop or purchase the necessary technological infrastructure to help clients navigate and access services.

3. There should be guidance/messaging from the state to MCOs to contract with a consortium of CBOs addressing a full range of social determinants within a community and NOT cherry pick CBOs. If we are truly to tackle poverty and support an infrastructure of health & human services on Long Island, there needs to be an investment in ALL SDH, through a holistic, person-centric system in which medical services are just one piece of the support puzzle for families and communities.

In fact, around the country, state governments, MCOs and health providers are boldly investing upfront dollars in SDH and CBOs, convinced that the result will be improved health outcomes and reduced Medicaid costs. Here are some notable examples:

- In Toledo, Ohio, a partnership between Local Initiatives Support Corporation (LISC) and ProMedica, an Ohio health system, led to an investment of \$45 million in underinvested neighborhoods, promoting economic development and targeting the region's unemployment challenges.
- In Utah, Intermountain Healthcare has committed \$12 million upfront investment in The Utah Alliance for the Determinants of Health, focusing on two counties with the intent to replicate the model throughout the state.

- In Michigan, person-centered, multi-sector collaborations with an equity lens are driving most of the Medicaid reform initiatives.
- In Denver, Colorado, UnitedHealthcare is investing millions of dollars in affordable housing, including \$14.7 million in a Denver non-profit that provides education, training and support for children and adults with developmental & intellectual disabilities.
- Since 2010, California's Health in All Policies ensures a focus on health, equity and sustainability in policy-making across all sectors.

According to a recent publication by the Robert Wood Johnson Foundation, "State Medicaid programs can only be truly successful if they are responsive to the needs and priorities of the clients they serve-not providers, but patients and their families." We applaud New York State for the work to date to move towards a healthcare delivery system that values improved outcomes as much as dollars saved. But there is much more to be done and we hope our recommendations will help steer the next phases of this work.

Thank you.



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October 17, 2018

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.

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,

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

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 only¹¹ 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.

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 OPWDD 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

OPWDD 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

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 system¹⁵ 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.

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/mcmaid_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 OPWDD 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

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, 633.11 Medical 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

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

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:

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

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 placed 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.

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.

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

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.” *Benio 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.

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Good Afternoon Chair and Co-Chair and members of the Project Approval and Oversight Committee. I am Hannah McIntire, the Chief Operating Officer of the Arab American Family Support Center. At the Arab-American Family Support Center, we have strengthened immigrant and refugee families since 1994 by promoting wellbeing, preventing violence, getting families ready to learn, work, and succeed, and communicating the voices of marginalized populations. Our organization serves anyone who is in need, but over our nearly 25 years of experience, we have gained cultural and linguistic competency serving the growing population of Arab, Middle Eastern, Muslim, and South Asian communities.

We are an active member of the Brooklyn arm of the Citywide Communities Together for Health Equity (CTHE), where Brooklyn Perinatal Network is lead and Caribbean Women's Health Association is co-lead. We have over 20 agencies representing the diversity of the borough of Brooklyn in our hub. While we have 20 member agencies, we still have more small CBO's that need to be meaningfully engaged in this health care improvement process. Our member agencies are diverse geographically and linguistically. There is a plethora of social determinates of health negatively impacting our most vulnerable populations in Brooklyn. Our Hub members address a wide-range, including but not limited to:

Adult education and literacy/ job training programs, case management and crisis intervention, food security, social, family, community support and a host of other services. Our approach is multi-generational – serving individuals from birth to senior citizens.

In our 18+ months working together, we have made great strides through the CBO grant funding. However, we also identified many gaps, We want to stress these 3 areas:

1. The need for meaningful CBO inclusion in the healthcare delivery system at all levels, (governance, structure and decision making) is vital to the improvement of the health care delivery system
2. There must be a shared agenda for health equity inclusive of community engagement in its development
3. The need for improved and increased CBO capacity must be taken seriously, we cannot expect small CBOs that often see the most vulnerable populations will continue to exist and function on so little human and financial resources. Investment must be made in the communities.

We recommend the following actions in Brooklyn:

- Improve the referral mechanism between CBOs to link to each other (IT systems) for improved communications, service coordination, and service gap reduction; which can improve health outcomes;
- Localize the connection between CBOs, PPS's and MCO's – please note that some of us have had good relationships and involvement with some of the Brooklyn PPS's; such as the CCB of Brooklyn, serving on the Community Engagement Committee, NYU Langone, and involvement with OneCity. We need to continue to improve relationships and leverage resources to strengthen all.
- Enable CBOs to influence policy around housing and its impact on healthcare.

Examples of recommendations for the State:

- Take strong leadership to ensure that small CBOs are not excluded from the table as not being able to provide quality care, hence, only large organizations are being considered during major planning and funding opportunities
- Identify and find funding for the continuation and sustainability of the citywide CTHE
- Ensure that we protect NY's immigrant population that may be impacted against the proposed changes in public charge
- Facilitate that all transparent bi-direction communications occur with CBOs, MCOs, PPS and the State.

Thank you for your attention. As always, the Arab-American Family Support Center stands ready to work with you in ensuring the most vulnerable among us thrive.