As New York State begins to transform the entire delivery system through Medicaid Redesign, Medicaid Matters New York (MMNY) looks at the Delivery System Reform Incentive Payment (DSRIP) program in terms of how real people will interface with a newly-transformed system, how the providers and community-based organizations that serve them will continue to do their work, and how the Medicaid program will continue to meet the needs of everyone it is intended to serve.

MMNY submits the following comments regarding key areas of interest and concern to Attachments I and J, as they are intended to govern the implementation of Performing Provider Systems (PPS) and the DSRIP projects, along with the Special Terms and Conditions agreed upon by the Department of Health and the Centers for Medicare and Medicaid Services (CMS):

**Transparency and Accountability**

MMNY applauds the level of transparency and accountability required throughout the implementation of DSRIP. Public disclosure of PPS applications, including participating providers and chosen projects (through the posting of the Letters of Intent and Design Grant applications, for instance) will afford advocates and community members the opportunity to examine the intricacies of DSRIP as it is taking shape. MMNY encourages DOH to utilize us and other advocates as resources and knowledge-brokers throughout the design process, as our intimate knowledge of community needs and capacities would enhance accountability as projects develop both at the state and local levels.

MMNY has long advocated for transparency and accountability in the allocation of public Medicaid funding and is encouraged that the DSRIP design reflects this transformative effort.

**Attribution**

A significant focus of health care system transformation must be on the experience of the consumer and the diversity of people within and between communities across the state. The DSRIP attribution methodology does not incorporate individual preferences, cultural differences and subjectivities, or health and socioeconomic disparities. It is unclear how race and ethnicity, primary language, disability, and other dimensions of diversity are considered, if at all, in PPS designation. Health care disparities are a major factor in problematic use of the health system that DSRIP funding is meant to address. Racial differences are only tracked in Domain 4, and disabilities are not tracked at all [see section on addressing health disparities below].

Uninsured residents are counted in use of the health system for safety net designation, signifying a population of need. Yet, only Medicaid beneficiaries are attributed to a PPS. DOH has raised
concerns as to how to count the uninsured; MMNY submits that there are sources of information available, such as the American Community Survey, and Exhibit 50 of the Institutional Cost Report and Federally Qualified Health Center state reporting mechanism. If uninsured residents are left out, access to care will become even more difficult for them. Uninsured individuals must not be left out of PPS considerations; doing so will jeopardize health access and care for New York’s most vulnerable residents, increase health disparities, further fragment care delivery, and potentially raise the burden of unnecessary utilization.

MMNY requests that the DSRIP attribution model incorporate a methodology that acknowledges disparate disability, ethnic, linguistic, and geographic groups, as well as individuals who are uninsured and ineligible for, or eligible and currently unenrolled in, Medicaid.

**Community Engagement**

Although the DSRIP documents make mention of the involvement of community residents and organizations in PPS development and planning, this effort will not work unless there is ongoing, meaningful involvement of consumers and consumer advocates. The same is true for community-based providers and organizations that should be made part of each PPS. MMNY requests that DOH create a specific structure and timeline for involvement of community residents and organizations in PPS development and planning, which should include meaningful efforts to include consumers and consumer representatives in that process. An inclusive community engagement process could include, but should not be limited to:

- Mandatory community involvement in planning meetings between members of a PPS when addressing the community needs assessment and selection of DSRIP projects;
- Participation of community members, organizations, consumers and consumer representatives in the independent review process of DSRIP final applications; and,
- Recognition of individuals or community organizations in each geographic area that could provide expertise to each PPS in development of a community needs assessment and project selection.

A series of Medicaid member focus group meetings were convened upon the development of the original MRT waiver amendment in 2012. The Medicaid Director and staff toured the state and sat down with Medicaid consumers to engage them in conversation about what the state should achieve under a new waiver application. Those meetings should be replicated as part of stakeholder engagement in the DSRIP, particularly because the content of the waiver amendment is drastically different than it was when those meetings took place.

**Community-Based Services**

The DSRIP strategy menu (Attachment J) suggests a number of potential projects to provide “evidence-based strategies in the community,” especially for chronic disease control, self-care and prevention. This is a very important part of reforming the delivery system; chronic disease education and self-care strategies can routinely be delivered in the community both more affordably and with wider reach, especially reaching high-need populations that tend to avoid the medical system.
The community groups often best equipped to provide evidence-based strategies for disease prevention and self-care in the community do not necessarily hold a current integrated role in the delivery system. For many “non-traditional” providers, DSRIP participation would represent their first opportunity for Medicaid funding beyond grants and state aid. Independent living centers, for example, have a strong track record of improving the health of people with disabilities, but have been viewed as an add-on in some of the other efforts at care coordination, such as Health Homes. For the state to truly achieve the aims of DSRIP, DOH will have to provide technical assistance to community groups to the same extent it provides assistance to lead agencies. Technical assistance must be clearly designated and available to community groups for the following purposes:
- Recognition of geographically appropriate PPSs with which to form partnerships;
- Coordination with potential PPS partners for inclusion into DSRIP networks;
- Assistance in providing information and expertise to the community assessment process;
- Organizational data collection on participants and outcomes; and,
- Infrastructure and capacity development, regardless of planning funds distributed to the other members of the PPS.

To this end, the state should create a designated “Office of Technical Assistance” within DOH with special representatives for community groups to enhance the opportunities for “non-traditional” providers.

**Care Coordination and Case Management**

MMNY supports the Department of Health’s efforts to enhance and expand care coordination and case management services to Medicaid consumers through DSRIP; it is clear that care coordination is an essential component and a high priority of this new delivery system. This focus on case management is essential in addressing many of the barriers that low-income New Yorkers face in accessing care and reaching the health improvement goals of the DSRIP. However, there is a lack of clarity in the Special Terms and Conditions and Attachments I and J about what case management services are, how consumers will access them, and whether the services will be provided in a meaningful way.

For example, case management connectivity is the first priority listed in the DSRIP’s attribution methodology. As there is no definition of case management in the glossary, it is not clear which definition of case management services DOH is referring to; it may refer to case management services as defined in the Federal regulations and/or the Medicaid managed care model contracts. It is also not clear if a PPS that provides these services will also assist consumers who need less intensive case management but do require navigation assistance.

Although the project goals described in Domain 2 of Attachment J indicate the importance of care coordination in the DSRIP, it is not clear how this new delivery model will expand case management services to consumers. In fact, Domain 2 does not refer to case management services, and presumably not all PPSs will provide case management. This lack of clarity will potentially lead to confusion for consumers. For example, it is not clear how a consumer would know that he or she is attributed to a PPS that provides case management services.
Further, it is not clear how case management services provided by a PPS will be coordinated with the case management services already provided by Health Homes and managed care plans. The Special Terms and Conditions identify a specific role in participation and funding for Health Homes, but do not clarify their position to a PPS and correlated insurance plans. Clarification on roles and responsibilities, particularly for assessment and service planning, must be identified before provider systems identify community needs. Further clarification on the role of financial accountability and oversight must be provided so that providers of case management in CBOs, Health Homes, and managed care plans understand their rights and responsibilities prior to final provider system and project development.

Finally, the role of managed care plans in providing case management services must be clarified within this new delivery model. Case management provided by a PPS must be coordinated with the same services required by plans, but without overlap and with clear roles and expectations delineated for consumers. Medicaid consumers must have access to information about seeking assistance when they experience barriers to accessing services or navigating the PPS in relationship to their insurance product. To the extent that case management services are provided by a CBO working with a PPS, the CBOs should be able to maintain the independence needed to advocate for consumers in their community. It is important that consumers be able to continue to seek assistance with appeals and Fair Hearings from CBOs.

In seeking clarity, the following questions / issues should be addressed:

1) Define the components of case management, and any services or activities that are excluded.

2) Clarify whether case management is voluntary, and for which members case management is mandatory if applicable.

3) Delineate safeguards to ensure consumer confidentiality.

4) Clarify whether participants can choose their case manager, and whether participants will have meaningful choice in case management provision, including information about how a participant would identify and select a new case manager.

5) Assurances that case managers are not able to limit services otherwise provided by the Medicaid state plan, with a clearly identified appeals process for consumers in the case that state plan or otherwise eligible services are denied.

6) Identify which participants are eligible for case management services and how a participant becomes eligible or loses eligibility.

7) Provide a description of staff qualifications and structure for each model/definition of case management.

8) Set case load limit in policy and procedures to maximize effectiveness and prevent staff burnout, with a methodology that respects the risk stratification no more conservative than that approved for managed care plans.
9) Define the process for soliciting client feedback on current and planned programs and services.

10) Define the methods for ensuring that consumers are aware of steps for filing a grievance and/or appeal of case management decisions and explain the interrelatedness with appeals of service determinations.

11) Explain interrelationship between disease management and case management, including related responsibilities for oversight, accountability, and coordination between relevant providers.

Health Disparities

Health disparities are an important driver of the outcomes that this waiver seeks to address including the overall outcome of reducing avoidable hospitalizations by 25% over five years. It will be important for Performing Provider Systems to address health disparities to achieve the desired outcomes.

Numerous studies have documented that people with disabilities are far less likely to access health care services than people without disabilities.\(^1\) Similarly, people with Limited English Proficiency (LEP) are more likely than non-LEP individuals to report being in poor health, deferring medical care, experiencing adverse drug effects, and are less likely than non-LEP individuals to have a regular source of care.\(^2\) Health disparities research suggests that valid and reliable data are fundamental building blocks for identifying differences in care and developing targeted interventions to improve the quality of care delivered to specific population groups.\(^3\) Hospitals and other health care organizations armed with data from their own institutions will be better equipped to look at disparities in care, design targeted programs to improve quality of care, and provide patient-centered care.

Yet the metrics identified in Attachment J do not provide an adequate method of tracking health-related disparities. In Domain 1, metric (1)(c) asks Performing Provider Systems to document the number of beneficiaries served through the projects, but does not further delineate disparate ethnic, linguistic, cultural, or disability populations. Domain 4, Population Wide Metrics, relies on the deficient SPARCS data which tracks measures for Black non-Hispanics and Hispanics, but does not yet track any other health disparities populations.

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Along with race and ethnicity, the Health Disparities Workgroup of the Medicaid Redesign Team recommended that DOH “implement and expand on data collection standards required by Section 4302 of the Affordable Care Act by including detailed reporting on...gender identity, the six disability questions used in the 2011 American Community Survey (ACS), and housing status.”

While CMS did change many of the ideas that came out of the MRT participation process, it should be aware of the need to track disparities populations beyond race and ethnicity. The Affordable Care Act now requires any “federally supported health care or public health program, activity or survey” must collect and report “to the extent practicable, data on race, ethnicity, primary language, and disability status, for applicants, recipients, or participants.”

Recommendations:

1) Performing Provider Systems should identify the race, ethnicity, sex, primary language, disability status, gender identity, and housing status of the beneficiaries they serve. They should do this so they can do a better job of serving them, comply with all applicable civil rights laws, and report the numbers and percentages for the purposes of overall project assessment.

2) Domain 4 projects should include population-wide metrics that measure the differences in health indicators for all health disparities populations including race, ethnicity, sex, primary language, disability status, gender identity, and housing status. The U.S. Department of Health and Human Services Implementation Guidance on Data collection standards should be used for race, ethnicity, sex, primary language, and disability status. LGBTQ advocates and housing advocates should be consulted for standards to measure gender identity and housing status.

3) The community needs assessment for each PPS must include the above relevant information on diverse populations correlated to health and health-related community needs such as housing, employment, culturally responsive social services, and community navigation services.

4) Reflect medically underserved communities in the expansion of potential DSRIP projects to include an opportunity for primary care, ambulatory care, or specialty services (such as behavioral health, cross-disability, prevention, maternal health, tribal health) to meet the needs of underserved populations.

5) Compliance with non-discrimination laws should be assessed as a requirement of the DSRIP project application review to ensure accommodation of people of different races, ethnicities, disabilities, gender identities, languages they speak, and other dimensions of diversity.

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5 42 U.S.C. 300kk(a)(1).
Social Determinants of Health

A review of current community health needs must reflect social determinants of health (housing status, employment, environmental factors, access to transportation, economic development opportunities), as well as an analysis of persons with disabilities living in both institutions and in the community. An analysis of health disparities alone will ignore the specific relationships between socioeconomic factors and population health. Furthermore, an analysis of the scope of community members with disabilities and their supports and services will identify specific service needs. Doing so should be a requirement in fulfillment of state *Olmstead* activities, maintaining that any health system transformation or policy initiative must take into account the community inclusion of all people with disabilities.

Department of Health Staff Structure

The Department of Health has undergone significant redesign of its own over the past few years, and it has been losing staff. Despite a significant portion of DSRIP work being done by outside entities, DOH has a major role in planning, data development, technical assistance, monitoring, and evaluation of DSRIP. It would be tragic for Medicaid Redesign to stagnate or not meet its full potential because of a lack of state resources or failure to transform and integrate departments. There should be clear recognition of the need for an investment in state staff, and DOH should publicly offer a strategic plan to transform and integrate state systems in direct relationship to Medicaid Redesign and 1115 waiver amendment activities. In addition, information should be posted as to the DOH organizational structure that will be dedicated to the work associated with DSRIP, and inter-organizational relationships to other agencies and policy planning processes.

Conclusion

We urge DOH to reflect considerably on the recommendations herein. Failure to address the needs of Medicaid consumers and uninsured, underserved community members will contribute to the ultimate failure of this historic systems transformation. We look forward to further communication with DOH on these issues and further implementation details of the DSRIP plan, and appreciate the Department’s continued commitment to the health needs, rights, and dignity of all New Yorkers.

Medicaid Matters New York is a statewide coalition of over 140 organizations united around the interests of Medicaid beneficiaries. Components of these comments were drafted by Belkys Garcia and Carol Santangelo of the Legal Aid Society, Chris Norwood of Health People, Heidi Siegfried of New Yorkers for Accessible Health Coverage, Briana Gilmore of the New York Association of Psychiatric Rehabilitation Services, and Judy Wessler.

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