

Submitted via e-mail 1115waivers@health.ny.gov

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Amir Bassiri
NYS Medicaid Director
New York State Department of Health
Office of Health Insurance Programs
Waiver Management Unit
99 Washington Avenue
12th floor (Suite 1208)
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Re: Comments in Response to New York's Proposed 1115 Waiver Amendments
[https://www.health.ny.gov/health_care/medicaid/redesign/2022/docs/2022-04_1115_waiver_draft_amendment.pdf]

Dear Mr. Bassiri,

We are submitting comments in response to the state's Proposed 1115 Waiver Amendments to express our strong recommendation that multiple elements of the waiver more deliberately address intellectual and/or developmental disabilities (IDD). While the proposed amendments are focused on Medicaid managed care, we believe there is significant opportunity to define the work of HEROs, SDHNs, and the design of value-based payment structures in ways that would acknowledge the meaningful number of beneficiaries with "hidden" IDD and/or who do not qualify for HCBS waiver services and who are being served in managed care organizations.

Institute for Exceptional Care (IEC) is a non-profit organization committed to transforming healthcare for people with IDD. IEC is working with broad coalitions of clinical organizations, payers, purchasers, regulators, consumer advocates, and social service professionals to improve systems and processes of care that support better health and life outcomes. In the Seamless Care Alliance of Nassau & Suffolk on Long Island, IEC and our partners aim to reduce avoidable emergency department (ED) visits, improve ED care, and ease transitions back to the community. SCANS seeks to strengthen care coordination between health systems, home- and community-based service providers, state and county agencies, insurers, and people with IDD and their families and caregivers. IEC is also collaborating with Montefiore Medical Center and Long Island Select Healthcare on a project to automate the comprehensive identification of people with IDD in clinical and claims data that could help address disparities and build a business case for better care.

Introduction Section of 1115 Waiver

IEC appreciates New York's focus on equity and its broad definition of sources of disparities that includes disability.

There is substantial research documenting poor outcomes for individuals with IDD, including increased risk for both [COVID infection](#) and [COVID death](#), [maternal mortality](#), [obesity](#), [diabetes](#), [mental illness](#), and [suicide](#). The intersection of IDD with race/ethnicity and poverty leads to even worse outcomes.

Many Medicaid beneficiaries with IDD do not receive HCBS waiver-provided services. According to national data, [in 2015](#), 67 percent of people on the HCBS waiver waiting lists had IDD.

Regardless of whether they are in fee-for-service (FFS) or MCOs, everyone with IDD would benefit from providers taking more deliberate approach to (1) flexible communication and service modalities; (2) engaging Home and Community Based Services (HCBS); and (3) taking the burden of coordination off of patients and families. New York should ensure that HEROs, SDHNs, and MCOs focus explicitly on IDD.

HEROs

IEC supports the state's proposed creation of Health Equity Regional Organizations (HEROs). HEROs bring MCOs, providers, QEs, SDHNs/CBOs, and other stakeholders together in a collaborative governance structure, but it is crucial that people with IDD are in leadership roles. These lived experiences would ensure that HEROs take into account the needs of the IDD population.

MCOs

IDD is poorly documented in clinical charts and insurance claims, likely due to a combination of under-recognition by clinicians, the lack of payment rationales for coding, and patients not self-disclosing, among other reasons. Our analysis of claims from a national insurer suggested a prevalence rate only 10-25% of what would be expected based on surveillance data from the Centers for Disease Control and Prevention or from survey data. A separate analysis of national electronic medical record data showed a drop of over 50% in the ostensible prevalence of IDD between late adolescence and young adulthood, suggesting poor fidelity of diagnostic documentation during the transition from pediatric to adult care. We would thus strongly suspect that Medicaid MCOs in New York serve a significant number of people with IDD.

“Hidden” IDD can explain avoidable clinical complications and spending in Medicaid. Lack of awareness of a person's underlying IDD condition may lead to [“diagnostic overshadowing.”](#) inadequate communication or other forms of support that could improve health literacy and behaviors, and missed opportunities for targeting specific clinical and non-clinical interventions.

We agree with [previous public comments](#) that this waiver proposal should include resources to more reliably identify beneficiaries with IDD.

Social Determinant of Health Networks

IEC also recommends that the waiver proposal broaden the categories of qualifying services from SDHNs to include HCBS services, which are of potentially high-value to

beneficiaries with hidden IDD who have not applied for the HCBS waiver, or are languishing on the wait list. Beneficiaries without IDD may also benefit from HCBS support.

IEC also encourages the State to set clear expectations that SDHNs should allocate a meaningful proportion of their funding toward investments in staffing and infrastructure for the community based organizations within their networks, which have struggled with chronic underfunding and further depletion of staff during the pandemic. Without such investments on the ground, SDHNs will be challenged to partner with CBOs in sustainable ways.

This proposed waiver amendment shares many elements with those being implemented in [North Carolina's](#) waiver. But we note a key difference between the two states – North Carolina has mandatory assignment for beneficiaries with IDD, significant behavioral health disorders, or traumatic brain injury, into tailored managed care plans, regardless of their status regarding HCBS waiver services. With the exception of Partners Health Plan, which has extremely modest enrollment, New York does not currently offer the same comprehensive “wrap around” within a managed care context. This waiver proposal presents an opportunity to more deliberately design programs and payment structures for beneficiaries with IDD who are served by general Medicaid MCOs.

In conclusion, IEC applauds the State for a proposal that directly addresses social determinants of health and equity, and that offers regional leaders the flexibility to define priorities and craft solutions most meaningful for their communities. But to do so without deliberate and comprehensive attention to IDD risks once again excluding this most vulnerable population from participating in health system changes that could have deep impact on their lives, thereby reinforcing some of the very inequities the State purports to solve.

Sincerely,

Institute for Exceptional Care
Hoangmai Pham
President & CEO