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July 13, 2021

Theodore Kastner, MD
Commissioner
New York State Office for People with Developmental Disabilities
44 Holland Avenue
Albany, NY 12229

Dear Commissioner Kastner:

The Healthcare Association of New York State, on behalf of our member nonprofit and public hospitals, nursing homes, home health agencies and other healthcare providers, appreciates the opportunity to comment on the New York State Office for People with Developmental Disabilities plan to invest in New York's home and community-based services with enhanced funding distributed through the Centers for Medicare and Medicaid Services' Federal Medical Assistance Percentage funding.

HANYYS supports OPWDD's efforts to use appropriated federal funding to enhance, expand and strengthen the support and services provided by OPWDD. The pace of community-based service expansion has struggled to keep up with the demand and longstanding gaps in care for individuals with intellectual and/or developmental disabilities persist.

A timely and seamless care continuum is imperative to prevent crises and ensure that people with I/DD have the opportunity to achieve the highest level of independence and quality of life. Strengthening home- and community-based services is instrumental to developing this care continuum. HANYYS urges OPWDD to use enhanced FMAP funding to build on ongoing efforts to create a timely and seamless care continuum that recognizes the growing complexity of care needs for individuals with I/DD.

Comprehensive crisis services

Despite OPWDD efforts to make crisis care available through the *Crisis Services for Individuals with Developmental Disabilities* program and the *New York's Systemic, Therapeutic, Assessment, Resources and Treatment* program, individuals experiencing an I/DD behavior-related crises are often brought to the hospital when they would be better served in the community.

Emerging models for mobile crisis response and stabilization are promising, but currently do not fully meet the needs of the many individuals living with co-occurring I/DD and behavioral health disorders. Ensuring a timely and appropriate crisis response for this population will minimize significant disruptions for these individuals and their loved ones, and reduce unnecessary law enforcement involvement and emergency department visits.

HANYS recommends that OPWDD expand and make NY START available statewide. Currently, NY START teams are not adequately resourced to provide the crisis response and support needed; nor are the services available in every region. HANYS also recommends OPWDD use the enhanced funding to support the CSIDD program.

Respite care

Over the years, New York state has greatly reduced the availability of respite services. Respite services provide critical support to families who want to have their loved one remain at home with a family member. HANYS suggests that OPWDD use some of the enhanced FMAP to continue to fund and provide these services.

Improve interagency coordination and collaboration

HANYS strongly recommends that OPWDD work with both the New York State Office of Mental Health and the Office of Addiction Services and Supports to develop a full, comprehensive crisis response system, understanding that people presenting with I/DD and co-occurring disorders are the expectation, not the exception. Crisis response for individuals with co-occurring conditions that fall under the purview of two or more agencies is critically needed, especially for adolescents with I/DD and behavioral health disorders.

Workforce

There are critical shortages of home health and other direct support professionals throughout New York. The lack of well paid, qualified and highly trained DSPs has been an ongoing challenge for years and is now exacerbated by the pandemic. HANYS recommends OPWDD use enhanced FMAP funding to increase compensation for these individuals and assist with workforce recruitment and retention.

Recognizing complex care needs

Individuals with I/DD are often brought to the hospital when crisis care, community support and residential beds are inadequate or unavailable. Increasingly, those with complex care needs then become stuck in the hospital for months, even years, after they are ready for discharge. Hospitals are currently serving as a long-term destination rather than a way station for those who, once their acute care needs are met, are better served in a non-hospital setting.

According to hospitals, the number of people with complex care needs is growing and the discharge delay problem is escalating. Unnecessary discharge delays and hospitalizations pose undue risks to patients and can result in irreversible deterioration of progress toward independence. These delays also disrupt acute care delivery by exacerbating bed shortages, presenting safety threats and causing significant moral distress among staff, all at an avoidable enormous cost.

Hospitals have adapted to best meet the needs of patients and are expertly engineered to provide acute care in the short term, but hospitals are not an acceptable place to live.

HANYS' white paper, [*The complex case discharge delay problem*](#), describes the devastating impacts of months- to years-long discharge delays experienced by people with complex care needs, many of whom live with I/DD and/or co-occurring conditions.

As OPWDD develops plans to expand and strengthen home- and community-based services, HANYS implores OPWDD to recognize individuals with complex care needs and offers the following suggestions:

- identify mechanisms to understand the extent and scope of individuals with complex case needs experiencing I/DD and co-occurring disorders;
- ensure that the pace of change in service delivery can adequately meet demand;
- develop consistent behavioral rules and practices for state, regional and county agencies, community-based providers and other stakeholders to ensure these vulnerable populations receive timely and well-coordinated care;
- reestablish interagency councils that were intended to ensure communication across systems and between state and local decision-makers; and
- explore ways to achieve parity for reimbursement of I/DD services to increase access to care in an environment where reimbursement is significantly lower than the cost of providing care.

HANYS appreciates the opportunity to provide feedback and is here to support OPWDD through these deliberations. If you have questions regarding our comments, please contact me at 518 431.7730 or jgold@hanys.org, or Sarah DuVall, director, behavioral health, at 518.431.7769 or sduvall@hanys.org.

Sincerely,

A handwritten signature in black ink, appearing to read "Jeffrey A. Gold". The signature is written in a cursive style with a large, stylized initial "J".

Jeff Gold, Esq.
Senior Vice President and Special Counsel, Managed Care and Insurance

