

Medicaid **Medicaid Matters New York** *Matters*

Independent, individual advocacy assistance for people with I/DD: Create the ombuds program for people with I/DD in this year's budget

Medicaid Matters New York, the statewide coalition representing the interests of people served by Medicaid in New York, calls on the Governor and Legislature to create the independent intellectual and developmental disability ombudsman program. People with I/DD, their family members and their advocates need individual assistance navigating the complex system of services and care coordination intended to provide for their needs and choices.

We thank Governor Hochul for including \$2 million in the Office for People with Developmental Disabilities (OPWDD) budget to create the program.

Thanks to Senator John Mannion, the Senate one-house bill includes the provisions of S.3108 (sponsored in the Assembly by Assembly Member Marianne Buttenschon, A.1577), which would create the program in law. **We need this Article VII budget language to be included in the final budget.**

This program would:

- Provide individual assistance to people with I/DD, their family members and advocates;
- Be available statewide;
- Advise and advocate on individual cases and concerns; and
- Provide accessible education on various aspects of state programs and CCO services.

Some advocacy and assistance programs for people with I/DD do currently exist, but they are earmarked for specific reasons for specific populations, and they are not readily available statewide.

Independent individual assistance services of this type are already available to people enrolled in Managed Long Term Care (MLTC), Health and Recovery Plans (HARP), and the Fully-Integrated Duals Advantage program for people with I/DD (FIDA-IDD) through a program called the Independent Consumer Advocacy Network (ICAN). Similar services are available to people seeking mental health care and treatment for substance use disorder through a program called the Community Health Access to Addiction and Mental Healthcare Project (CHAMP).

According to anecdotal reports, the Care Coordination Organizations (CCOs), in place since 2018 to provide essential services previously provided by the Medicaid Service Coordination (MSC) program, do not universally operate in ways that allow people and their advocates to successfully navigate the care coordination system. CCOs are charged with assessing individual needs and wishes, helping individuals execute a Life Plan, and ensuring Life Plans are successfully implemented.

March 2023

People with I/DD deserve an independent avenue for addressing their concerns. CCOs have internal mechanisms for addressing individual concerns. In addition, the state has a network of regional offices administered by the Office for People with Developmental Disabilities (OPWDD), one function of which is to address individual issues that arise with the CCOs. Neither the CCOs nor the state regional offices adequately address people's concerns and are not independent.

Such issues may include (but are not limited to) failure of a care coordinator to be responsive to individuals in their case load, individual dissatisfaction with how their Life Plan is being implemented, failure of the CCO to provide adequate training of care coordinators, and more.

On and off for several years, OPWDD has explored the possibility of imposing mandatory enrollment in Medicaid Managed Care for people with I/DD. People need assistance services whether their services are moved to managed care or not. Should managed care be implemented, assistance services related to managed care could be integrated into an already-existing assistance program.

The Office of the Advocate for People with Disabilities was reinstated in 2022. We applaud the Governor for making the commitment to advance and protect the interests of people with disabilities within her administration. An independent advocacy assistance program is still critically important. While it would be funded by the state, it would operate independently. The independent nature of the program is vital, as people with I/DD need a venue for resolution of issues accessing services and navigating the complex system intended to serve them, some of which are provided and/or authorized by the state.