

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

Testimony to the Assembly Ways and Means and Senate Finance Committees  
Joint Legislative Budget Hearing on Mental Hygiene  
February 16, 2023

Thank you for the opportunity to provide testimony. Medicaid Matters New York is the statewide coalition representing the interests of the over seven million New Yorkers served by the Medicaid program. Over 100 coalition members participate in our advocacy. They are people covered by Medicaid, family members, community-based organizations, community-based providers, legal services agencies, policy and advocacy organizations, statewide associations, and more.

Medicaid Matters believes New York needs a Medicaid program that delivers quality health care and services to all who need them. While not perfect and gaps remain, New York Medicaid has a long history of providing care and services to meet the needs of low-income people and people with disabilities.

Medicaid Matters urges the Legislature to accept the \$2 million in this year's proposed budget to **create an independent individual advocacy assistance program for people with intellectual/developmental disabilities (I/DD)**. Additionally, the enacted budget should **include legislation to codify the program** by including the language of Assembly bill 1577 (Buttenschon) / Senate bill 3108 (Mannion). The legislation includes important guardrails to make sure the program is run by an appropriate independent entity. It also delineates some of the functions the program should include.

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.

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.

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.

Such a 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).

On and off for several years, OPWDD has explored the possibility of imposing mandatory enrollment in Medicaid Managed Care for people with I/DD. The Governor's budget includes a five-year extension of the authorization for implementing managed care (which Medicaid Matters opposes). People need assistance services whether their services are moved to managed care or not, and there are some people who are enrolled in managed care on a voluntary basis who would benefit from these services.

The Governor reinstated the Office of the Advocate for People with Disabilities 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.

Medicaid Matters welcomes your questions and dialogue regarding this program. We urge the Assembly and Senate to include the legislation to create the program in your one-house budget bills, and we stand ready to help make sure this program comes to fruition this year.

Contact information:  
Lara Kassel  
Coalition Coordinator  
Medicaid Matters New York  
lkassel@medicaidmattersny.org