

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

Anniversary Reflections Collected as of November 27, 2023

Medicaid Matters New York is 20! What a milestone. Congratulations to everyone who has been a part of this incredible organization for the last two decades.

I remember the beginning of MMNY so clearly...the one-two punch of then-Governor Pataki and former President George W. Bush releasing damaging state and federal budget proposals within days of each other with the intent to gut Medicaid and place a bull's eye on our state's poorest and medically at-risk individuals and families. Organizations who represented people who relied on Medicaid came together quickly to mobilize and fight back.

We held emergency conference calls and in-person meetings and named ourselves the New York State Medicaid Defense Group. We wrote position papers. We organized lobby days. We wrote press releases and letters to the editor. But probably more than anything else, we recruited other like-minded organizations and individuals to join us, growing the organization while always emphasizing that this coalition represented Medicaid enrollees. While member organizations had their own individual missions and foci – whether it be abortion rights, HIV/AIDS advocacy, or issues impacting seniors – our commonality in the defense of our state's Medicaid program and the people it covered gave us power and a unique voice.

We ditched the "Medicaid Defense Group" name for the catchy and more positive sounding "Medicaid Matters New York." We branded our materials, grew our membership list, and strategized regularly now. We were united, had a simple and straightforward message, and took advantage of our member organizations' strengths – financial, political, and otherwise – to fight. That first year we were able to beat back most of Governor Pataki's state Medicaid cuts and we were instrumental in organizing a strong push back from our Members of Congress – Republican and Democratic both – to oppose Bush's block grant proposal. Year one was by most accounts a success. MMNY's work was successful and people started to notice. And thus MMNY began.

From a personal perspective, this was a special time. I cannot say exactly why, but there was a mood, a feeling, a unity in purpose that made the stars align and good people come together. In a state known for special interests and big money dictating health care decisions, MMNY stood out. We represented the people on Medicaid and the belief that Medicaid, does indeed, matter.

- Laura Caruso, GMHC

What stands out in my memory of the early days of MMNY is unshakeable sense of shared purpose. We brought together so many threads of program knowledge, different consumer experiences, some of us with legal perspectives, drug expertise, national advocacy platforms, labor backgrounds. We shared our different political analyses - experiences with 'the second floor', the agency, legislators from different boroughs, Long Island, upstate. Underlying all that, I think we shared a pretty profound respect for New York's Medicaid program. And we believed that the story people who depended on Medicaid had to tell about it should be and ultimately would be more powerful than any other narrative. So we carried those stories forward, over and over again, in meetings and pictures and fliers and "one-pagers" and "ten pagers" and reports and webpages. And we made a difference.

- Trilby de Jung, Empire Justice Center

I was one of the early members of MA Matters, representing Planned Parenthood of NYC. My vivid early recollections include the incredibly large and varied coalition that sat in one of the CSS conference rooms. The diversity of organizations, consumers and governmental agencies was more robust than many other coalitions that I have been part of in my many years of advocacy.

Trying to represent all the differing needs was a challenge and there were times when tempers ran amok and "civility" was not always the tone of the meetings. Government staff were invited to come and attempt to answer the barrage of questions that were flung at them. Some did better than others at responding; some returned for future meetings and some almost ran out of the room.

And yet despite all the passions and strong opinions expressed, our common goals remained the same: ensuring that those folks who who covered and/or were eligible for the MA program received what they were legally entitled to and received them in a way that was humane and respectful and relatively "user friendly." Before the term, "social determinants of health" became part of the vernacular, we all talked about the need to address a holistic approach to health and confront the endemic inequities of race and class within the health care and public insurance systems.

It was a great honor to be part of this group and to represent the reproductive health and justice movements at MA Matters. We never stopped advocating for what we all fundamentally believed in and indeed, did impact how the eligibility process was better tailored to our clients, how health care was delivered and how public insurance was and remains a basic human right.

- Alice Berger, Planned Parenthood NYC

I recall monthly meetings of the Health Care Campaign, when the reports of our workgroup on Medicaid began to take up so much time. With issues of the utmost importance in a year with draconian budget cuts being proposed in the Executive Budget, the workgroup spun off into the Medicaid Defense Group. Oh, those "good old days" when we hoped that attacks on Medicaid were a temporary phenomenon limited to George Pataki's administration! Onward to constant threats and the Medicaid program viewed by budget policymakers as the "problem in the budget" rather than a solution that ensured people of abject poverty necessary cradle to grave health coverage. Ultimately the Group was reborn as the premiere Medicaid advocates representing the consumer voice: Medicaid Matters NY. Happy Anniversary - thanks for the great work, and how I wish system changes were adopted so our advocacy was no longer needed.

- Gail Myers, NYS Nurse Association and StateWide Senior Action Council

In 2011, Governor Cuomo's Medicaid Redesign Team decided to make Managed Long Term Care mandatory for everyone receiving home care services. At that time, there were a small number of advocates in the state who had been assisting clients with Medicaid home care issues, mostly without dedicated funding. This small, loose network quickly realized that moving tens of thousands of high-need Medicaid recipients into managed care plans was resulting in a flood of transition-related issues. To meet this surging demand, talk turned to establishing a statewide ombudsman to provide funding and coordination to this network of advocates. But with an administration bent on drastic cost-containment and "managed care for all," how realistic was it to get state funding for advocacy services? Especially when those very advocates were often perceived as a thorn in the side of the Medicaid program? Despite these obstacles, Medicaid Matters helped brainstorm and advocate for the ombudsman program, and in 2014 it became a reality. Now called ICAN, the MLTC ombudsman has advocated for over 40,000 consumers over the last 9 years. It has provided a bulwark against disruptions in care or unnecessary institutional placement for older adults and people with disabilities.

ICAN also provides valuable feedback to the state Medicaid program on trends, to help support systemic change. None of it would have happened without Medicaid Matters. Thank you, Medicaid Matters!

- David Silva, Evelyn Frank Legal Resources Program and Independent Consumer Advocacy Network

With the caveat that time seems to shape memories to what we would like them to be rather than what actually happened, in my mind I cannot disconnect the founding of the Medicaid Defense Group (then MMNY) with what had happened two years prior in the wake of 9/11/2001: Disaster Medicaid. Out of unspeakable horror, an experiment was born where we saw so many people getting access to necessary health care. In a new and profound way we saw the potential for how Medicaid could impact so many lives for good. At least personally, I know this post 9/11 experience lit a fire and created a resolve that something more had to be done to defend a critical program for so many New Yorkers, especially those living with disabilities and seniors.

Sorry I can neither be with you all in person nor have any pictures to share. For those who remember my spouse, Kate Lawler, please know she sends greetings as well. Thanks to all of you who have carried on this work in New York State.

The years have erased most of the specific memories, but one that has stood the test of time is of an early Albany lobbying visit to a less-than-friendly legislative staffer. When the letterhead and list of coalition members was presented to him, he said something to the effect that this is just the usual cast of characters organized under a different name. "Refried beans" or not, clearly twenty years on MMNY has stood the test of time and the particular alchemy of the forces that came together on behalf of NY Medicaid consumers released a force to be reckoned with.

- David Wunsch, GMHC and Center for Independence of the Disabled in NY