

Governor Cuomo's Medicaid Redesign Team's Cuts Harm Beneficiaries

“...and it won't impact beneficiaries.” - Governor Andrew Cuomo, January 21, 2020, speaking of his Medicaid Redesign Team

Require 2 or more ADLs for CDPA or PCA services



Blaise B. - Albany - Blaise B. receives Consumer Directed Personal Assistance (CDPA) services because he is legally blind. He receives level one services only for assistance with IADLs. He receives eight hours/week of services for laundry, grocery shopping, sorting mail, meal preparation, and maintenance of his physical environment (cleaning and trash removal). Without this assistance, he is unable to maintain a professional role, receive adequate nutrition, live in a compromised hygienic environment, and more, placing him at increased risk of a range of additional complications and higher cost service needs. In addition to his professional work, Blaise volunteers in the community and is a member of various groups. This would not be possible because he would need this time to attempt to perform these basic tasks.



Rebecca W. - Ithaca - Rebecca has been diagnosed with Severe Myalgic Encephalomyelitis (ME/CFS), Postural Orthostatic Tachycardia Syndrome (POTS), Mast Cell Activation Syndrome (MCAS), and Fibromyalgia. Due to her diagnoses, Rebecca is bed bound for 23.5 hours per day. It is only with the assistance of her worker that she can continue to survive and thrive in the community, using the Medicaid Buy-In for Working People with Disabilities to access CDPA. She also, despite all of her diagnoses, only needs assistance with one ADL. Her entire life in the community would not be possible if not for CDPA.



Joyce M. - Albany - I am approved for 8 hours of personal care/week for light housekeeping & grocery shopping. I was having trouble getting an aide assigned to me from my MLTC plan's home care agency. So, I went into self-hire instead through the Consumer Directed program. I have COPD and can't manage on my own, but with just a little personal care assistance I am able to live at home and still be part of my community, go to church and attend my senior meals. Changes to the number of ADLs to qualify will mean that I will have to rely on my neighbors to help me out, when they can. That's not fair. That's not safe. I don't belong in a nursing home.

KB, age 45 - Erie County - KB has a seizure disorder and frontal lobe and executive function deficit, caused by a swimming accident in the ocean, when a boat did not see her and she was pinned to rocks. She has 20 hours/week of Consumer Directed Personal Assistance, for which her mother is the main personal assistant. She is ambulatory and her gait while slow is mostly steady. KB reports that while she can perform most of her ADLs on her own, KB has a cerebral spinal fluid leak that drains through her ears and nose at times, which causes dizziness. Other symptoms of her condition lead to exhaustion and forgetfulness, and constant headaches.. This has led her to leave her stove on after cooking, forget her medications, fall in the shower, and more. Her needs are primarily for supervision, oversight and cuing for the following tasks:

- meal preparation, shopping, and ordinary housework
- managing medication
- transportation
- Bathing, dressing, and personal hygiene
- locomotion
- toileting

She is easily fatigued and has to take frequent rest periods during activities. She spends a lot of her time going to medical appointments. Without the approval of CDPAP for supervision and cuing, KB would be at severe risk of harm.

Sanjay, 66 - Sunnyside, Queens - is a former cab driver who lives with his wife of 30 years, Eva, age 51 and their two sons, ages 12 and 15. Sanjay was forced to stop working at age 61 because it became unsafe for him to drive due to early onset dementia. Eva struggled to raise her sons and manage her husband's increasing care needs while working full-time, getting home at 6 PM. She sought help for him to apply for Medicaid and enroll in MLTC, which approved home care and adult day care, but the MLTC schedule left him alone between 3 - 4.5 hours on weekday afternoons, and approved no care on the weekends. Sanjay appeared to be in good shape physically, except for needing insulin that Eva administered. But his cognitive impairment had grown to the point where he needed cueing and prompting assistance with all ADLs so could not be alone. His doctor wanted him to use a walker but he needed to be reminded to use it constantly. His day care gave him van transportation home, but he would then become hopelessly lost trying to find his own apartment in the building where he had lived with his family for years. He would go to the bathroom and urinate everywhere except for the toilet. It was initially believed that he did this because the walls and floor and toilet of the bathroom were all the same color but day care staff reported that he exhibited the same behavior in the daycare center's high contrast bathroom—he simply could no longer identify the toilet. Similarly, he needs help transferring to a chair because he has difficulty understanding that it is a place to sit. When the MLTC plan denied additional hours, claiming Sanjay was able to walk, toilet, and transfer independently, a Fair Hearing decision cited Sanjay's doctor's opinion that Sanjay could not perform any ADL without cueing and prompting and awarded him additional hours to ensure that Eva had enough time to get home from work at 6 pm and run errands on weekends to properly take care of the household. If eligibility is restricted to those needing "limited" assistance with ADLs, defined in the UAS as physical assistance, and not cueing and prompting, Sanjay would be ineligible for MLTC or personal care entirely - and would have been forced into a nursing home years ago.

Richard F. - Broome - Richard is totally blind and receives five hours a week of CDPA service. He lives alone so is dependent on his worker to assist him with grocery shopping, and other such errands. She also helps him with laundry, since the washer in his building is inaccessible to blind people. Additionally, she takes him shopping for clothing, and to run certain errands that may come up that are necessary to his independence. If he didn't have the service, he would have to pay someone to assist him, and he is low-income so wouldn't be able to afford it.

Nita A, a 69 year-old Latinx woman living in the Bronx - has dementia, schizophrenia, diabetes, and incontinence. She was going to her Senior Center during the day and MLTC approved an Aide for the evening and nights to assist her with her Activities of Daily Living (ADLs). After falling at the Senior Center, she was hospitalized and the family realized she was not safe at the senior center without an aide's assistance, and asked the MLTC plan to increase her hours to 24 hour care. The plan denied the request, claiming she needed only "safety monitoring" not assistance with ADLs. Due to her cognitive impairment, Nita does not realize her limitations and must be reminded to use the walker and to perform proper hygiene after toileting, and needs "contact guarding" assistance when she walks – which means

someone hovering close by to give support as needed. The lack of cueing assistance with ADLs puts Nita in jeopardy of injury, infections or death as those with physical needs.. Nita ended up back in the hospital and is now in a Nursing Home. Her NYLAG advocate just won her fair hearing directing the MLTC plan to increase her hours so that she can be discharged home. If the law is changed to restrict eligibility to those needing physical assistance, Nita would be forced to remain in the nursing home, where she is unhappy and has expressed longing to return home.



Robert M. - 85, DeKalb Junction, St. Lawrence County - Bob is a Medicaid beneficiary who has 24-hour care due to heart problems, diabetes, and mobility issues, among other conditions. He requires help with all ADL's including walking, eating, bathing, drinking. He lives in senior housing in DeKalb Junction where he is able to conduct his life as a community leader organizing meetings for elders in the County Council, giving information on issues concerning community living, and ensuring that others are aware of resources available to him. In the past he has spent time in nursing homes and says that he would not go back because his quality of life suffers greatly. He credits his homecare workers with being able to maintain a productive and comfortable life in the community and feels that anything less than what he has will not be conducive to aging in place.



Laura J., 86 - Massena, St. Lawrence County - Laura is a Medicaid Beneficiary who participates in the Consumer Directed Program. Over 2 years ago Laura suffered a blood clot on her brain that warranted a stint in a nursing home in Syracuse for rehabilitation. Upon release from the nursing home, Laura was approved to 18 hours of care / week. Her sister has taken on the duties of caregiver doing her shopping, cleaning, and home making duties. Laura, who uses a walker, suffers from weak ankles, chronic arthritis, and COPD. She runs out of breath easily and can only stand for a few minutes at a time. She says that without her sister's help, she would not be able to continue living a productive life in the community volunteering at nutrition centers and serving in leadership positions in her local

senior services groups. If she can't hire her sister to provide care, Laura will end up in a nursing home instead of a vital part of her community.

Enhanced Utilization review (put high hour folks in a nursing home) -



Kendra Scalia, M.P.P. - Newburgh NY (Orange) - “Born with Spinal Muscular Atrophy, I use a power wheelchair for mobility and receive intermittent respiratory support via mouthpiece ventilation. I'm a trained healthcare policy analyst (UC Berkeley, '07) and currently volunteer my skills to a policy consulting firm I founded in 2018. I also serve on the Board of two not for profit organizations. CDDA means I'm able to continue the work I love and live in my community. My personal assistants provide up to 16 hours per day of ADL and IADL assistance for me to maintain my health, independence and dignity. The MRT II recommendation for "enhanced utilization review" means I'll be caught in a catch-22 of proving I'm disabled enough for the amount of care I need, but not too disabled that I won't be safe in my home. I've lived 18 years on my own without family support and with no unplanned hospitalizations because of CDDA. My safety is impacted only by the threats to the program that would modify eligibility requirements, place additional barriers to eligibility, and reduce reimbursement rates, which directly impact my employees' wages.”

Sandra L. - Nassau - Sandra receives live-in services for a condition that has remained unchanged since she was 13 years old. In 2013, she was forced to change MLTCs to remain with her current FI. The new plan informed Sandra that they had determined it was unsafe for her to live in the community and that, if she wanted to receive any services, she would have to go into a nursing home. This was news to Sandra, as she had been living successfully in her accessible home for over 50 years, was working, paying taxes, Fortunately, Sandra was connected to people who could help her fight this and she did not have to go to a nursing home. People have the right under the Americans with Disabilities Act (ADA) to live in the least restrictive setting possible. Sandra wanted to live at home. This proposal allows high hour users of service to be harassed until they have a bad day and can be “justifiably” forced into a nursing home.

Eileen, age 83, - Baldwin NY - Eileen lives alone and has a primary diagnosis of severe dementia. She had been hospitalized multiple times in the past few years -- in 2016 for a broken pelvis, and in 2017 due to frostbite after leaving her home, becoming lost for hours in frigid weather. In August 2018, she was ready for discharge home from a Long Island rehabilitation facility, which recommended 24-hour care. Her treating physician examined her

and wrote, “She is living with dementia, but otherwise in good physical health. I can see firsthand how she has deteriorated. She is unsafe to carry out a sequence of tasks and it would be unsafe to perform basic self-care activities such as bathing, dressing and cleaning herself after toileting. It would be a danger to her to live in the community without 24-hour supervision.”

Upon discharge, her MLTC plan authorized only 7 hours/day of home care, which her family voluntarily supplemented by paying for additional care, at financial hardship to them. A month later, an appeal was successful requiring the MLTC to increase home care to 24/7. She needs to be reminded to use her walker when ambulating - which can be any time due to impulsivity, characteristic of the disease. She requires prompting and cueing to wash her hands after toileting, and to remind her of how to use toilet paper instead of stuffing it into her clothing. Her aides report that she often gets up multiple times at night to toilet because she forgets that she had already completed the task. If only the need for “limited” and not “supervisory” assistance counted when assessing if the consumer has two ADL needs, she would be denied home care and forced to remain in a nursing home. It is also clear, based on past experience, that “enhanced utilization review” will be used as an attempt to eliminate her 24/7 services and force her into a nursing home, even though with such services she is living successfully in the community.



Mike V. - Albany - Mike has needed 24-hour service for almost 20 years, but has been using the consumer-directed style of personal assistance since he started college in 1983. Five years ago he had a tracheostomy installed and began using a ventilator. The staff at the hospital insisted he had to go to a rehabilitation center in another county instead of taking a few minutes to train him and his personal assistants on the simplicity of using and maintaining the respirator that keeps him alive and comfortable. This entry to a facility was against Mike’s wishes, with him insisting it was a “huge waste of time and expense that was unnecessary”. It took all of Mike’s advocacy skills that he acquired over his life, along with the work of a longtime friend and former college roommate, who is a disability rights attorney, to demand and force his release. Without such a large effort, he might still be there five years later, which also means he would have lost his apartment and his CDPA service. Because Mike’s need for constant PA service is on the more extreme side of things, he knows that managers and social workers be convinced that he cannot be independent, completely ignoring everything he has proven for the last 37 years. He knows he is always under constant threat of being accused of incapability by professionals who could force him into an institution, despite decades of evidence that he does not require such service and does not want to leave his community..



Diane P. - Rockland - Diane is confined to her home most of the time due to ambulatory issues and multiple chronic illnesses. This is where she wants to live. She has both Medicare and Medicaid and is enrolled in Managed Long-Term Care. She is approved for a home health care worker 12hours/day: they shop, do laundry, clean her apartment, help with bathing, and make meals. If she no longer could qualify for Medicaid home services, her only option would be a nursing home. She was a certified long-term care ombudsman and she says the conditions in nursing homes are horrific. She will not go and says she would rather die in her home do to neglect than go to a nursing home.

Zach - Hudson Valley - Zach is a 31-year old quadriplegic who lives in his own home, has his own vehicle, and has two part-time jobs. He's mentally sound and able to run my own affairs; but requires 24-hour care as he is unable to transfer, needs help with meal preparation, bathing, toileting, etc... Currently, Zach's care manager works well with him and recognizes how well he does in the community; however, on multiple occasions, those with power over his life have suggested that "he would just be better off in a nursing home." Zach disagrees; but, knows that with a monthly review of his services, he is just one bad care manager from institutionalization.

Spousal Refusal

John S - Manhattan - John has been on Medicaid since 1994. After years and years of dating his current wife, they overcame their nerves and got married in 2005. Their nerves were not about their relationship, they were about the "Marriage Penalty" Medicaid imposes on disabled people and their spouses. John uses the Medicaid Buy-In and a trust to utilize his CDPA. His wife undertook the difficult process of spousal refusal so that she too could pursue her career and still practice one of those most basic of human rights, marriage. John and his wife have 3 year old twins, and the elimination of spousal refusal means they will have to explain to these two why Mommy and Daddy have to get divorced.

Betty and Bob - Erie County - In their Mid-60's, they had just transitioned into retirement and taken on some debt to live out their dreams of spending summers in the south and winters traveling in their motor home. Bob has a stroke and their world turns upside down. Wife petitions Supreme Court for Guardianship and is successful. She makes an application for Skilled Nursing Home Medicaid. Betty does not have assets anywhere close to the maximum spousal impoverishment allowance - she is drowning in debt. She is forced to go back to work full time. Makes about \$4,000 /month gross but to keep up with household expenses/debt and living costs for someone her age that works full time, she needs the money. She signs a spousal refusal for her excess income. Eric County brings a Petition in Family Court for support.

The Eric County Attorney and counsel work together to scrutinize her income v. expenses and come to agreement for a reasonable income contribution.

Cristina H, age 66, life-long resident of Manhattan's Lower East Side, was never able to return to her work as a special education teacher after undergoing five rounds of surgery for cervical cancer in 1994. Her Social Security is \$1735 per /month and her husband's is \$2400/ per month. More than half of his income pays spousal support to his ex-wife, which is not deductible by Medicaid. Their rent and living expenses eat up the rest of their income. Her annual drug costs under Medicare Part D without the "Extra Help" subsidy would be \$3500 per /year. With spousal refusal, Cathy qualifies for the Medicare Savings Program without counting her husband's income. The Medicare Savings Program pays her Part B premium, saving \$144.60 per month, and qualifies her for the Extra Help subsidy, which reduces her prescription costs to only \$150/ per year.

MARIE Z. - Bronx- Marie was age 60 when she was diagnosed with early onset Alzheimer's disease in 2015. She had been a homemaker and never worked. Her husband, also age 60, earned about \$1800/week gross (about \$1200/week take-home). Until she was 65 recently, he paid their health insurance premium combined \$1805 per month. They have a rental apartment in their house in the Bronx with net rent of about \$540/mo. Their expenses include mortgage of \$2171.53 per month, property taxes of about \$9,800/year, home owners insurance \$4,600/year, utilities of \$300/mo., car payment of \$250/month, food, clothing and other expenses. NYLAG helped her obtain Medicaid and home care and then renew it for several years, enabling her to remain home with her husband as her condition progressed. She would have about a \$2500/month spend-down if her husband did not execute a spousal refusal, which would leave them at risk of losing their house.

PARENTAL REFUSAL EXAMPLE - Serena, 9-year-old child rendered quadriplegic by Guillain Barre (East Elmhurst, Queens) – The Rusk Institute at NYU Medical Center referred this Latino family whose only child, age 9, had her SSI discontinued when her father obtained a better job. The child is quadriplegic since having Guillain Barre, is on a ventilator and has a tracheostomy that requires suctioning. She has CDPAP care through a mainstream Medicaid managed care plan. The father's income of around \$54,000/year (around 250% FPL) is too high for the child to qualify for MAGI Medicaid through the Affordable Care Act, but is far from enough for the family to pay the cost of 24-hour care the child needs. She can keep Medicaid if her father uses "parental refusal." This will be necessary only temporarily – as she is likely eligible to apply for the Children's Waiver, which will not count the parents' income. But that could take months or longer, and in the meantime Parental Refusal ensures continuity of critical medical care and home care. Also, CDPAP services save the State money, as they are a fraction of the cost of a Private Duty Nurse, that would otherwise be necessary because of the skilled needs.

Regina B.- Erie County - Regina is a community spouse in her 60s, working as a paralegal. Regina, the community spouse, had to execute a spousal refusal because even though low, her income was just over the spousal impoverishment allowance. Also, she had built up a modest

retirement account over decades of hard work. Because the retirement plan allowed her to withdraw from the retirement account for emergency medical purposes for her spouse, Erie County determined it was an available asset. Spousal refusal enabled her husband to get coverage so that she could preserve her retirement account for her own retirement to avoid impoverishment.

Dorothy and Anthony (ages 93) – Hicksville, Nassau County – Dorothy, now 95, needed home care 2 years ago because the family, especially her husband (Anthony) who was 92 at the time but is now 94, was providing the care for her and it was just getting too much. She is bed-bound, obese, with advanced dementia, incontinent and difficulty swallowing. Their combined assets of \$45,000 were within the spousal impoverishment budgeting limit of \$75,000 but that limit isn't allowed when first applying for Medicaid to enroll in an MLTC plan. On application, only \$23,100 assets are allowed for a couple (2020 limit). Before applying, Dorothy's assets had to be transferred to Anthony, who did a spousal refusal. Once she enrolled in MLTC, he was entitled to spousal impoverishment budgeting.

Anthony came to the United States after World War II from Poland, where he worked on the farms. They worked and raised their family on minimal means and he was extremely upset that he needed to ask for this assistance from the government. At the time of the application – their combined income from Social Security was \$1941/month, for which every penny was needed to pay monthly expenses. Plus he drew money from his annuity in the amount of \$15,000 that year to pay bills, including property taxes of \$6277, which skewed his income to appear higher that year for the Medicaid application. Without spousal refusal for both income and assets, Dorothy would have been denied Medicaid. Once enrolled in an MLTC, spousal refusal was no longer needed as Anthony's income and assets were within the spousal impoverishment limits. Dorothy continues to have 24-hour live in care through an MLTC – at home with her husband rather than an institution.

ROB & SUSAN - Manhattan - "My husband and I still felt like newlyweds when he became desperately ill 30 years ago. He needed a newly approved life-saving procedure and we couldn't pay for it. He had Medicare which had approved the procedure--but not yet implemented the approval. We had no time to wait and Medicaid covered the procedure. I spent my days in a panic because my father had loaned me \$8 thousand dollars years before and I paid it back--during the look back period. And, we were just enough over income that spending down would have turned over our small boat. We weren't millionaires not even close. Someone explained to me that we might have to get a divorce to keep him alive. I couldn't even imagine divorcing my husband while he fought for life.

Somehow, we learned about spousal refusal. Writing the letter about our situation and saying that I would not pay his expenses is one of the hardest things I've ever done in my long life. But, my husband lived because New York State had a way to help us. He was accepted for

Medicaid and he got his life-saving procedure. Soon afterwards, Medicare paid Medicaid back after it implemented its approval of the procedure.)

He has lived to see his daughter grow up, to become a prize-winning story teller and he is still the love of my life. All thanks to Medicaid's Spousal Refusal. It is such a small, but necessary program. I am shocked and desperately sad that lawmakers could take it away. I don't think that they could even imagine that ordinary people like my husband and me would need a program like this. Well, that's just wrong."

Mr. K. - Mr. K is a Korean-American senior, age 77, living in Flushing, Queens, has been permanently disabled since his advanced prostate cancer metastasized. One of his cancer medications – Zytiga -- costs \$8,800 per month, even with Medicare Part D. He is eligible for the Medicare Savings Program if only his own Social Security income of \$1369/month is counted, but his wife's Social Security of only \$600/month puts him over the income limit. They have no savings. With spousal refusal, he qualifies for the Medicare Savings Program, which automatically gives him Extra Help with Part D, reducing his drug cost to \$8.25/month. New York pays NONE of the cost of the "Extra Help" subsidy for his prescriptions – it is fully paid by the federal government. NYLAG helps him renew this benefit every year.

LOOKBACK – Transfer of Assets

Meg - Meg was diagnosed with Parkinson's disease in 1999, when she was just 43. Over the years her symptoms worsened--immobilizing rigidity characteristic of Parkinson's disease rendered her helpless during symptom onset. Her doctor considered her a model patient, logging her medication administration and symptoms in a journal so that her doctor could titrate her medications with the progression of the disease. Eventually she could not continue to live independently without home care. She paid privately \$40,000 per year for home care, spending down her savings from her career in publishing and from selling her father's house in Maryland. By October 2017 she had exhausted all but \$50,000 in stocks, which she transferred along with her co-op apartment in Brooklyn into an irrevocable trust. She then applied for Medicaid and enrolled in MLTC. Her condition continued to progress, and as is typical, the Parkinsons' meds wear off and symptoms re-emerge or worsen at unpredictable times, resulting in the need for an increase to 24-hour split shift home care. It took months for this increase to be authorized, and she had to supplement her MLTC hours with private pay care using the money she transferred into the trust. Had there been a transfer penalty, she would have been denied Medicaid and forced to spend down her excess assets, making them unavailable to supplement her needs later when she urgently needed them. That may have landed her in the hospital or a nursing home.

Amy was age 93 and had dementia when her daughter died of cancer and left her \$200,000. Shortly after her daughter's passing, Amy fell at home. She was hospitalized and then, while she was in sub-acute rehab, the apartment above Amy's flooded and almost all of her belongings were destroyed. Unable to bring Amy back to her wrecked apartment, and

unable to take Amy in to their own homes, Amy's surviving daughter and son moved her into an Assisted Living Facility in the Bronx which charged about \$5000 per month and which ordinarily neither child nor Amy could afford. Fortunately, Amy had transferred her deceased daughter's \$200,000 to her son, who has been paying for the facility for the last 3 years out of these funds. Transferring the money also allowed Amy to apply for Medicaid to access homecare through an MLTC to meet her extensive needs as her dementia has progressed, assistance which the assisted living facility does not provide. Had there been a lookback when Amy applied for community Medicaid, she would have had to leave the assisted living and go to a nursing home, as she would have been denied Medicaid to pay for home care. She could not remain in the assisted living without supplemental Medicaid home care. She is now nearly age 96 and still well cared for in the assisted living..

COVID-19 Testing and Overtime



Gloria E., 65, Bushwick, Brooklyn, NY - Gloria is dually eligible. She is on chemotherapy, has rheumatoid arthritis, is diabetic among other conditions. She is receiving 7 hours of care / day. She is enrolled in the Consumer Directed Program where her sister provides 35 hours of care and an aide provides 14 hours. Gloria is concerned that since there is no Coronavirus testing, and the aide has to travel by train from another neighborhood, and in her weakened state, she may be susceptible to Covid-19. Therefore, Gloria wanted to discontinue the services of the aide and see if her sister could expand her hours to care for her during that time. The insurance company and the care program say that they do not want to pay overtime and, so, they will put the aide on hold and the sister will have to provide services with no pay. Home care workers are not getting tested to go into homes of seniors and vulnerable population and ensuring that the patients will be safe. Family members must be able to provide care in the consumer directed program.

Delay implementation of CFCO services until April 1, 2022 -

CFCO Delay jeopardizes Federal funding - The state has collected over a billion dollars in additional FMAP since implementing CFCO. However, their failure to fully implement the program continues to place these funds, as well as future funding, in jeopardy. During the crisis, services such as CDPA and personal care, for individuals at a nursing home level of care, will actually receive 64% FMAP because of the combination of increased CFCO FMAP and Families First FMAP. With Local share being approximately 11%, this means the state is actually only paying less than one-quarter of the cost for these services.