

Empire Justice Center

NYS Joint Legislative Hearing on Nursing Homes, Assisted Living, Home
Health Care and COVID-19

Testimony of
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My name is Alexia Mickles. I am a staff attorney with Empire Justice Center's health law unit. Empire Justice is a non-profit, state-wide, multi-issue, multi-strategy, public interest law firm, focused on changing the "systems" within which poor and low-income families live. Our mission is to make the law work for all New Yorkers, especially for those who need it most. I work out of our Rochester office, serving clients from outside New York City, but primarily those who reside in Upstate and Western NY.

We have heard a lot during these hearings about the devastating impact the pandemic has had on long term care facilities. An important aspect of my job is helping people access and keep the long term care services that they need to let them remain in their homes, and to avoid nursing homes in the first place.

I want to share two client stories with you. At the beginning of 2020, we represented two similarly situated clients. Both are elderly, living with various ailments including advancing dementia, and had family members willing to both volunteer and work as caregivers in order to keep them at home through the Consumer Directed program. Both faced a reduction in their services by their managed long term care (or MLTC) plan that would render it impossible for them to remain safely in their homes, and both appealed through the fair hearing system. Despite rigorous advocacy, these families endured entirely different outcomes.

While one client had her case heard before an Administrative Law Judge and received a favorable fair hearing decision, keeping her in her home in the community immediately before the start of the COVID-19 pandemic, the other client's case was never heard on its merits. The appeal process itself - that final level of protection before home care services can be reduced - failed her. Instead of remaining safely at home, she languishes in a nursing home during the pandemic, and still has yet to have her case heard six months later. Two similarly situated clients, enrolled in the exact same plan, both fiercely represented by the same attorneys, and yet living completely different lives during these unprecedented times. This is not the system that our elderly population deserves.

Today, I want to highlight three themes we see during the pandemic and offer a few recommendations:

1. The Need to Keep Seniors at Home

Despite the benefits of staying in one's home rather than entering a facility, state policy still favors nursing homes over home care for Medicaid beneficiaries. At Empire Justice Center, we believe everybody - not just the wealthy - should be able to receive the medically necessary services they require in order to live safely in the community, if that is their choice. We need to avoid incorrect assumptions about safety being found only in an institutional setting, and ensure that the system supports and respects the basic rights of aging and disabled New Yorkers who cannot afford to pay privately for home care. Not only is that the most dignified way for our clients to live, but it is also the most cost-effective. As has been highlighted by Consumer-Directed Personal Assistance Association of New York State in their written and oral testimony presented on August 3, 2020, the state costs of nursing homes is significantly higher than the Consumer Directed program.

These facts make it clear that keeping seniors in their homes is a safe and cost efficient way to mitigate the risks presented by long term-care facilities during the pandemic.

2. Systemic Unfairness in Maintaining Home Care Services

The process by which low-income New Yorkers obtain and maintain their Medicaid-funded long-term care services is neither simple nor intuitive. Even with representation and before the pandemic, this was a grueling task for our clients. DOH has chosen to require that the vast majority of Medicaid recipients who require long-term care must enroll in a Managed Long Term Care Plan (MLTC) in order to access the services they need. MLTCs are private insurance companies that determine the amount, duration and scope of services their enrollees can receive.

DOH pays each MLTC a capitated rate per enrollee in the plan: in other words, the plans receive the same dollar amount per month for each of their enrollees - regardless of the services those enrollees require or receive. This creates a dangerous incentive: the MLTC profits on enrollees with relatively low needs, but stands to lose money on those with relatively high needs.

In the months leading up to the pandemic, we saw an uptick in MLTC plans seeking to reduce home care hours, particularly for those who receive 24 hour continuous (or “split-shift”) care and have some level of advancing dementia. When someone receives a notice of reduction, there is very little dialogue between the plan and their family or representative. The only course of action is to formally appeal the determination. The Medicaid appeal process is complex with confusing notices and critical deadlines. Upon receiving a notice of denial or reduction, the enrollee must first request an internal appeal. The MLTC has 14 days to complete this appeal, which may similarly be extended 14 days.¹ In our experience, MLTCs routinely ignore the regulatory deadlines for completing internal appeals. Furthermore, it is extremely unusual that an MLTC reverses itself on appeal. It is only once the MLTC decides to uphold its initial finding, by issuing Final Adverse Determination, that the individual can request a Fair Hearing – which is the opportunity to argue against a decision made by a local social services agency or health plan before a DOH Administrative Law Judge. The hearing itself is scheduled and overseen by the Office of Temporary and Disability Assistance, and federal regulations require that it be held, and a written decision issued, within 90 days.² Again, in our experience, due to a variety of factors that are often outside of the individual’s control, it is unusual for a hearing to be completed and a decision issued and implemented within this timeframe.

Altogether, it can easily take more than six months between an individual starting the appeal process and receiving a fair hearing decision upholding the long-term care services necessary to keep them safely in their homes and avoid the need to move to institutionalized care.

Despite this protracted timeline, the deadlines for our clients to respond and appeal determinations are extremely tight, especially for those who need to maintain their services while the appeal is pending. If a deadline is missed, there is very little recourse. If there is no “aid continuing” then families are forced to make the choice – move their loved one prematurely to a nursing home or face mounting bills as they attempt to pay out of pocket for aide services and/or lose wages while they struggle to provide the care themselves. When the time comes for the hearing, it is quite literally David v. Goliath for those without legal representation. The MLTC plans are prepared and they know the system. They are often represented by attorneys or have designated teams or staff who regularly handle appeals. They typically submit hundreds of pages of documentary evidence that the Medicaid recipient receives only a few days before the fair hearing. We have heard time and time again from our clients that it would be almost impossible for them to navigate the complex appeal process, let alone succeed, on their own.

¹ 42 C.F.R. § 438.404.

² 42 C.F.R. § 431.244(f)(1).

The inherent systemic unfairness in obtaining, but especially maintaining, healthcare services has only been exacerbated by the pandemic. Many low-income seniors and their families faced the untenable situation of defending against termination or severe reduction of essential services without any meaningful way to fight back against the decision. The current appeal process is unfair and woefully inadequate. The pandemic both accelerated and worsened those structural inequities years in the making. All of these factors – this uphill battle to secure and maintain services – will only be compounded by the pandemic.

3. Barriers to Timely Legal Representation During the Pandemic

We have heard at length in the August 3, 2020 testimony about the issues of maintaining direct contact between residents and families during the peak of COVID-19. While many have focused on the devastating social and mental health impacts, we want to highlight barriers to legal representation.

Since the beginning of the pandemic, many seniors who used their resident nursing facility as their mailing address did not receive mail notices relating to their Medicare, Medicaid or MLTC plan coverage or, even more pressingly, notices relating to potential discharge from the facility. Further, many did not know about their exiting rights under the law or resources available to help them. These twin obstacles often made it too late, or too difficult for low-income seniors to navigate a complex system already stacked against them. We saw a number of situations where the senior either received important notices late, or lacked the capacity to understand the significance of these notices. On at least one occasion, the delay resulted in loss of Medicare, and the right to appeal its termination.

The difference between receiving these notices in a timely manner, and not receiving them; having legal representation, and not having it -- can result in life changing consequences for seniors and their families. It is imperative that better guidance are issued about what duties fall upon the nursing homes to ensure that residents not only receive and understand these communications, but that they also receive timely access to outside agencies and services.

RECOMMENDATIONS

COVID has forced us to look hard at long term care facilities. The pandemic has worsened and underlined existing inequities for low-income seniors in nursing homes. We are at a unique moment, and New York has an opportunity to meaningfully improve its policies surrounding long term care. I would like to leave you with our three most pressing recommendations:

1. Invest *more*, not less, in home care services for Medicaid beneficiaries – including the Consumer Directed program.
2. Continue to fund organizations that can help New Yorkers obtain and maintain their Medicaid services. This includes a wide range of agencies from ombudsman and community-based organizations to legal service providers.
3. Impose a duty of care on facilities to provide information to residents and their families regarding ombudsman and legal services. Empire Justice Center is ready and willing to work with you to make this happen.

Thank you for this opportunity.

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