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VIA ELECTRONIC SUBMISSION TO REGULATIONS.GOV

Andy Slavitt, Acting Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-3260-P
P.O. Box 8010
Baltimore, MD 21244

Re: Proposed Rule for Long-Term Care Facilities, CMS-3260-P

Dear Andy Slavitt:

MFY Legal Services, Inc., submits these comments on the Centers for Medicare & Medicaid Services's proposed regulations governing long-term care facilities.

MFY envisions a society in which no one is denied justice because he or she cannot afford an attorney. To make this vision a reality, for more than 50 years MFY has provided free legal assistance to residents of New York City on a wide range of civil legal issues, prioritizing services to vulnerable and underserved populations, while simultaneously working to end the root causes of inequities through impact litigation, law reform and policy advocacy. We assist more than 20,000 New Yorkers each year.

MFY's Disability and Aging Rights Project serves residents of institutions in New York City, including adult homes and nursing homes, as well as people seeking to maintain their homes in the community so they do not become institutionalized. Through advice, individual representation, and impact litigation, we work to ensure that nursing home residents receive necessary health services while addressing abuse, fraud and waste in the health care system. We submit these comments informed by the experiences of our clients, nursing home residents who deserve to be treated with dignity and receive quality care in the least restrictive setting appropriate to their needs.

The proposed rules take an important step toward improving care at long-term care facilities by emphasizing the importance of "person-centered care" as defined in the proposed section 483.5. We are concerned, however, that moving resident rights to regulations governing facility responsibilities diminishes the independence and importance of those rights. We are also

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concerned that the new definition for “resident representative” will unintentionally restrict the ability of family and friends of residents to access information and advocate effectively on behalf of a resident.

MFY’s specific comments on particular proposed rules are aimed at strengthening the focus on the needs of individual residents. We begin with some suggestions for modifications to regulations that would advance the core value of person-centered care. The second section highlights some of the key aspects of CMS’s proposed regulations that MFY strongly supports.

Key Recommendations

MFY supports many of CMS’s revised and expanded regulations, but we offer the following recommendations to further strengthen the rules to promote high quality person-centered care.

483.10(a) Exercise of resident rights

MFY supports the expansion of this subsection to make clear that the resident is the focus at all times and the locus of control in all matters except for those in which a surrogate or court appointee has been specifically authorized to exercise certain rights on the resident’s behalf. The expanded language in subsection 438.10(a)(3) clarifies that the resident remains the locus of control even when she has designated a representative, and the representative’s rights only reach to those areas the resident chooses. Similarly, subsections 483.10(a)(4)(iii)-(iv) now make clear that a resident can still exercise her rights herself even when adjudicated incapacitated if the court order did not specifically assign those rights to the appointee, and that even in such cases, the resident must still be allowed to participate in her own care planning and her preferences must be considered. This section now requires nursing homes, representatives, and surrogates to respect a resident’s autonomy to the greatest extent her capacity will allow. MFY recommends adding language to subsection 483.10(a)(5) to clarify that it applies only when the resident has been found to lack capacity by her physicians, but has not been adjudicated incapacitated by a court. Adding that language would better distinguish the situation in subsection 483.10(a)(5) from the situation in subsection 483.10(a)(3), when the resident does not lack capacity and retains the ability to exercise all of her rights.

Several clients have complained to MFY that nursing homes seek decisions from incapacitated residents to avoid a surrogate, or seek out a surrogate when a resident is fully capable of making a particular decision. We believe CMS’s new language in subsection 483.10(a) will reduce nursing homes’ selective recognition of residents’ capacity.

483.10(b)(1) Information in appropriate language

Person-centered care and resident dignity require that residents receive all information in a language they can understand. The proposed regulation guarantees residents the right to “to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition,” and other parts of the proposed rule require nursing homes to provide certain notices in a language the resident can understand.

The rule must go further, however. Residents should always be spoken to in a language they can understand. A resident’s ability to participate in activities or interact with others is determined by

whether anyone around them can speak his or her language. But the right to be spoken to in a language one can understand is even more basic; it is at the heart of respecting a resident's dignity and personhood. The quality of a facility's care suffers when its staff cannot communicate with residents.

That deficiency can result in a client losing independence, and possibly, the opportunity to move to a more integrated community setting. Recently, for example, MFY was contacted about a client who wants to return to her home in the community. Her nursing home claims the resident, who is paralyzed on one side following a stroke and weighs less than 140 pounds, requires a two-person assist to transfer. In fact, when spoken to in her own (fairly common) language, she was easily able to transfer with one person's assistance. The lack of language access means worse care in the facility and substantially complicates discharge planning because her medical records indicate she needs far more assistance than she actually does. Rather than two attendants, she needs only one who can communicate with her.

483.10(c)(2) Choice of physician

The Nursing Home Reform Act guarantees residents the "right to choose a personal attending physician." 42 U.S.C. §§ 1395i-3(c)(1)(A)(i), 1396r(c)(1)(A)(i). MFY frequently hears from residents who do not like or do not trust the physician they have been assigned by a facility. We have also seen instances that raise serious questions about the level of care provided to individual residents by some physicians practicing in facilities. Choice of treatment is perhaps the most important right of residents in a person-centered approach to quality care. Limiting that choice to physicians credentialed by a particular facility unreasonably restricts that right, especially when the credentialing requirement in the proposed regulation does not set any objective standards for credentialing. The rule is open for abuse by facilities with an interest in maintaining administrative simplicity and diminished oversight, but provides no benefit to residents. The right to choose one's own physician should not be unnecessarily limited. As long as the physician is properly licensed by the jurisdiction, she should be able to see any patient, regardless of where that patient resides.

483.10(e)(2) Participating in the community

MFY supports this revision to explicitly protect a resident's right to engage with people and participate in activities outside the facility. MFY strongly recommends that CMS modify this revision to note that, in accordance with person-centered care, residents have a right to participate in activities or meet with people in the community outside the facility without an escort, unless an individualized assessment determines that an escort is necessary (for residents with advanced dementia, for example).

The right to engage with non-residents and participate in activities outside the facility is a hollow one if nursing home residents who are capable of doing so are not permitted to leave the facility without an escort. Although some nursing home residents have functional limitations, such as severe dementia or a history of wandering, which would pose safety concerns were they permitted to leave the facility without an escort, there are many nursing home residents for whom elopement or disorientation are not significant concerns. For some residents, it can be a substantial burden to arrange for an escort every time they would like to leave the facility for a

short trip to a nearby house of worship or a day trip to visit family or friends. For other residents, it is impossible, because they do not have family or friends.

Every year, MFY receives complaints from nursing home residents who are alert and oriented, are not at risk of wandering, and do not have dementia or similar conditions, but who are denied day passes to travel to and from a family gathering or other special occasion. Although it may not be a burden for family members in some parts of the country to escort their relative to and from a facility, in many places, particularly metropolitan areas like New York, Washington, Houston, or Los Angeles, a short distance can mean hours of driving or riding on public transportation in each direction. Such a burdensome time commitment on the family can mean the difference for a resident between attending the event and not. Many other nursing home residents do not have family, but might like to occasionally leave the facility for a social gathering at a house of worship or senior center. In at least one case in which a resident contacted MFY, the facility's refusal to issue a day pass meant the resident could not attend a housing court hearing to keep his apartment to which he planned to return.

A clear regulatory policy from CMS would mean a world of difference for residents who want to exercise the personal autonomy and right to participate in community events that the law ensures them. Many nursing homes explain that they have blanket policies that no resident may leave unescorted. Others argue that CMS would revoke their Medicaid license if they were to allow a resident to leave without an escort and an accident occurred. Person-centered care must, at a minimum, require facilities to evaluate a resident's appropriateness for unescorted trips on an individual basis.

483.10(e)(3) Right to visitation

To emphasize the person-centered care approach in visitation, MFY recommends additional language to ensure that facilities do not deny a visitor access if the resident does not object to the visit. MFY receives many calls from family members who visit or attempt to visit relatives in nursing homes who are turned away by the facility not because the resident objects but because a family member with more contact with the facility objects. The right to visitors is the resident's, and should not be exercised by anyone else without the resident's consent or a court order. We have found that often times, a family member serving as a resident's health care proxy overreaches and tries to isolate residents from other family members with whom the proxy does not get along. Although CMS's proposed rule should prevent these situations from arising, the fact that they do arise regularly suggests that more clarity is needed.

There are, of course, situations of abuse or exploitation where it is important to limit or prohibit a person's access to a resident. Those situations, however, should be dealt with formally, and not simply by relying on the word of one visitor against another.

483.10(f)(3) Access to records

Residents should have access to all types of records, not just medical records. The proposed change in this language is unnecessary and unwise. Furthermore, MFY is concerned that the added language authorizing labor costs to be billed to residents simply for obtaining their medical records is unnecessarily burdensome. Like in many states, most nursing home residents in New York receive only $50 of personal allowance per month. Without a per-page cap on fees

and an exemption for low-income residents, this revision will make it prohibitively expensive for residents to access records about their care.

483.21(c) Discharge planning

Discharge planning is by far the most common concern of MFY's clients in nursing homes. MFY supports CMS's expanded regulation of how discharge planning must be conducted and documented, but urges CMS to adopt an even stronger person-centered approach.

We believe subsection 483.21(c)(1)(v) should be rephrased to emphasize that residents and family members must be included in discharge planning from the beginning of the process to formulating the final discharge plan. The current language suggests that only minimal involvement is necessary, and that they can be simply "informed" of the discharge plan after it is created. Every client who contacts MFY could tell CMS that, if allowed to solicit this minimum standard of participation, nursing homes will produce high quality discharge plans for only the simplest cases. MFY recently represented a woman whose main nursing need was wound care for a static ulcer. The woman wanted desperately to return to her apartment, where she benefited from socialization at a senior center in her building with a wonderful director. Early in the client's stay at the nursing home, the senior center director would visit her, hoping that she would be able to return to her apartment and the senior center. She would have been happy to work with the resident and facility staff to create a safe discharge plan. Instead, at the request of the facility's administration, the senior center director stopped visiting, because facility staff found that our client's requests for discharge, spurred by these visits, were disruptive. Several years went by before MFY was contacted. The nursing home had simply refused to engage in discharge planning before our involvement, and, only after we insisted, applied to Medicaid home and community based services for the resident, who was accepted into the program.

Resident involvement is essential, but it is not enough. Short-term nursing home stays can easily last several months while a resident receives rehabilitation services following a surgery or other hospitalization. Residents' absence from their apartments and daily routines in the community for several months lead to additional problems that a nursing home must foresee and build into a discharge plan. For example, residents are likely to miss rent or mortgage payments, putting them at risk of eviction or foreclosure, which makes discharge substantially more difficult if not impossible. Many residents might require home care services, but might not be able to coordinate the many complex systems involved in arranging the care.

The revised regulations should require nursing homes to investigate a resident's community housing situation and take affirmative steps to assist the resident with preserving that housing. This responsibility must start in the first month of a resident's nursing home stay, before any adverse action is likely to be taken against the resident by a landlord or bank. For residents with spouses or nearby children, the added burden on the facility will be minimal. But a resident without these community supports will need the assistance of the facility with these issues while they focus on rehabilitation. Discharge planning for residents who need home care services should also include arranging such services either through a Medicaid provider, a Medicaid waiver program, or a privately paid agency, depending on the resident's resources and individual medical needs. A person-centered approach to discharge planning must require that a nursing home take these steps to assist a resident who intends to return home so that he or she is not forced to remain in a facility unnecessarily.

Every year, MFY represents nursing home residents who die before the nursing home effectuates a discharge back to the community. The importance of strengthening discharge requirements cannot be overstated.

483.35(a) Nurse staffing

Nursing staffing levels are probably the greatest single indicator of quality of care. We frequently hear from family members who visit relatives and find that diapers have not been changed, meals are delivered when they are no longer hot, and residents without visitors are provided with less care. One of our clients, who is seeking our help with discharge because the nursing home refuses to create a discharge plan, frequently waits for half an hour or an hour before a staff member responds to her activated call button for assistance with changing a diaper or getting out of bed. Sometimes the wait is so long, she uses her cell phone to call the nurses' station, but they still do not respond to her, simply telling her not to call them on the phone.

Requiring staff with skill sets matched to the residents they serve is definitely a step in the right direction, but it is not enough. Indeed, CMS has noted in its explanation of the rule that it believes most facilities already take an approach to staffing similar to that which CMS is proposing. The ratios facilities are using under that model are simply not sufficient to provide quality care. We have found that as formerly non-profit nursing homes are purchased by for-profit firms, staffing is being reduced. Many studies – including ones commissioned by CMS – demonstrate that when a nursing home has sufficient staff, the quality of care improves. Failing to provide basic care to residents reduces quality of life and increases the ultimate cost of care. Lower staffing ratios correlate to an increase in hospitalization for potentially avoidable medical problems, such as urinary tract infections for lack of proper hydration, sepsis, electrolyte imbalance, the incidence of pressure sores, and weight loss. MFY urges CMS to combine the competencies model with a minimum nursing staffing ratio.

483.70(n) Arbitration agreements

Although MFY appreciates CMS's recognition of the problem of mandatory arbitration agreements, we do not believe the proposed rules are workable. MFY urges CMS to ban the use of arbitration agreements in licensed long-term care facilities to protect the legal rights of residents. We join with New Yorkers for Patient and Family Empowerment, the New York Public Interest Research Group, Bronx Independent Living Services, Brooklyn Center for Independence of the Disabled, the Center for Independence of the Disabled in New York, Citizen Action of New York, Disabilities Network of New York City, Empire State Consumer Project, Gray Panthers New York City Network, New York Statewide Senior Action Council, Peggy Lillis Foundation, and PULSE of New York in a separate comment on this issue urging CMS to ban mandatory arbitration of resident claims against nursing homes.

In the alternative, MFY recommends adding a requirement to its proposed rule that facilities seeking a resident's consent to an arbitration agreement must inform the prospective resident and his or her family that they can reject the arbitration agreement and still be admitted to the facility. When a person is entering a long-term care facility, it is almost always at a hurried pace, if not for fear of losing an available bed at a certain facility, then because of extreme pressure from hospitals seeking to discharge patients promptly. Arbitration agreements are one of dozens of

forms and other papers given to residents and their families in the nursing home admission process. Unless families are told that they can reject the arbitration agreement with no negative consequences, subsection 483.70(n)(3) will have no effect.

483.70(p) Social work staffing

MFY believes the proposed social work staffing requirement is insufficient to accomplish the critical work delegated to that position. Among other duties, social workers coordinate benefits, communicate with family members, coordinate appointments and transportation, and, most importantly, take leading roles in comprehensive case planning and discharge planning. It is impossible for one full-time staff person to competently manage all of these responsibilities for 120 residents. Moreover, because social work services in nursing homes cover such a wide array of needs, MFY recommends that social work staff have formal training or in-service review of their responsibilities and the services and community resources that are available to residents.

Effective discharge planning requires a mastery of a resident's situation and coordination of Medicaid benefits, home care services, and the nuances of managed care. It also requires coordination with a resident and family and friends who provide informal support to a resident returning home. This is time-consuming work, and is only a part of the social work services offered at long-term care facilities. Without a better social work staffing ratio, the person-centered care CMS's revised regulations are intended to promote will remain elusive. Person-centered care requires individual attention, which cannot be met with a 1:120 ratio.

Key Improvements

MFY supports many of CMS's proposed revisions. Below, we have highlighted a few of the most important improvements.

483.11(d)(3)(iii)(B) Demonstrable responses to family council complaints

MFY strongly endorses this subsection based on complaints received from family councils at many homes. Residents' family members and family councils often report grievances to facilities, and just as often feel like their complaints are ignored. Facilities can ignore complaints with impunity, knowing that only the state surveyor can require changes. The demonstrable response and rationale requirement imposed in the revised regulations will guarantee that family members' complaints are at least reviewed. Even if the complaint is not acted upon, the family member will have an explanation for why, rather than simply feeling ignored. MFY is hopeful that this change will build a meaningful dialogue between facilities and their residents and their families to improve the quality of care.

483.11(f)(1)(i) Mail and package delivery

MFY strongly supports this change. Mail is a critical method of communication for nursing home residents, and receiving letters and packages, whether sent through the postal service, a courier, or by hand, is unreliable at many nursing homes. Residents frequently complain to MFY that they do not receive mail sent to them. Others receive time-sensitive mail several days after

it was delivered, or after it has been opened, or both. This spring, for example, MFY represented a client in a nursing home discharge hearing. The state's Department of Health sent an envelope with important documents related to the discharge hearing to the resident via certified mail, but it was not received by the resident for almost a week after it was delivered to the facility. In another case, MFY is assisting a resident with a home care assessment. We sent the client an envelope with only a self-addressed stamped envelope, so that the resident could easily send us a notice she had received from her managed long-term care plan. The resident never received our mail. These are just two examples of a widespread problem. Several residents urge MFY not to send them mail for fear that it will not be delivered or, worse, read by facility staff about whom the client complained to MFY. Residents with family who visit frequently often recommend that we mail important documents to the family members for personal delivery simply to avoid the facility's prying eyes.

The added language in the proposed rules is important because it broadens a facility's obligation to deliver confidential communications, no matter how they are received at the facility.

While receiving mail may seem antiquated, it is an essential means of communication with individuals and organizations outside the facility. Many of MFY's clients do not have telephones in their rooms, and must make calls from the nurses' station on their floor. We have heard complaints from residents without phones in their rooms that their facilities limit the number of local phone calls they are permitted to make from the nurses' station. Very few residents have access to computers or email. Sending and receiving mail timely and privately is one of the principal modes of communication available to nursing home residents, but it remains unreliable.

Thank you for your attention to these concerns.

Very truly yours,

/s/

Daniel A. Ross
Staff Attorney