

To: House Select Subcommittee

RE: Nursing homes

Statement for the Record

My name is Carrie Leljedal and I have a 34-year-old son who lives in an intermediate care facility for adults with developmental disabilities (ICF/DD) in New Baden, Illinois. I am also the state spokesperson and family advocate for Illinois Caregivers for Compromise, and I volunteer with other organizations advocating for residents in skilled nursing facilities.

My son Lynn Ray has lived in the ICF/DD for a little over nine years and has a variety of complex medical issues and is developmentally delayed, functioning around a 9-year-old level. We are very lucky that my son is in a good facility and that we live less than two blocks away, so my family can spend time with him easily.

Before March 2020 and the lockdown of all congregate settings, I knew very little about long-term care (LTC). I didn't know how little control I had when it came to seeing my son, accessing his current medical records, and or his daily activities.

Both my son and I were at a total loss when we were no longer allowed to see each other at any time we choose. Before March 13th, 2020, my husband and I would spend time with Lynn five or six days a week either at his facility or would pick him up and take him out for a few hours. Prior to March of 2020, I had never been away from my son for more than nine days.

I was not allowed to see my son in person for over 125 days, when I was finally allowed to see him, it was at a doctor's appointment. I was required to physically distance myself and I was forbidden to have any physical contact with my son. This was also the first time Lynn had been allowed to leave the facility in over 125 days. I can never describe how hard it was to be six feet away from my son and not be allowed to hug and kiss my son.

After that day, I decided that I had to find a way to have my voice and the voices of other families with loved ones in all types of congregate settings. Most people think of LTC and think that nursing homes only serve the elderly; this is only a small part of LTC. In the US there are close to 500 pediatric skilled nursing LTCFs, that serve children under 22 that require more care than their parents can provide at home. There is also a variety of LTCF servicing those with mental health issues, adults with developmental disabilities, veterans, and others depending on the needs of the residents. Adults ranging from their mid-20s through 65 with complex medical issues ranging from traumatic brain injuries, muscular dystrophy, multiple sclerosis, and many other illnesses, are one of the fastest growing groups moving into LTC today and most people don't even realize they live in LTC.

I knew the issue at hand was bigger than just what was being uncovered when all visitation was restricted in congregate settings. For close to a year, I spent day and night learning as much as I could about LTC and looking for ways to help all residents and families. The more I learned, the more I realized that the way we care for our most vulnerable populations in this country is unacceptable.

In 1987 the Nursing Home Reform Act established the minimum care standards for nursing homes and defines the legal rights of the residents in LTC. When HHS issues the 1135 waiver that allowed residents' rights to be violated due to Covid-19, it caused unforeseeable damage for residents in LTC. We will never fully know how many residents died alone from isolation, failure to thrive, malnourishment, bed sore, and other ailments and that is before we add in the number of covid related deaths.

We must find a way to provide better care for residents in LTC, while ensuring they are treated with respect, and dignity and provide the care they need and deserve. **Residents do not go into LTC to die, they go into LTC to receive the care they need while trying to maintain a quality of life.**

LTC needs a complete overhaul, we need to focus on what the residents truly need and how to provide the best care possible. Residents and their families from all types of LTC need to have a seat at the table to ensure their concerns, suggestions, and opinions are heard. Without input from the residents and families we will never be able to fix the issues at hand and make improvements in the future.

LTC like many other industries is dealing with the worst staffing crisis they have ever dealt with. We have all heard that the facilities do not have enough money to pay higher wages. We need better transparency before more money is thrown at the problem. Staffing minimums will help, but that is just the beginning. Facilities need to treat their employees better, showing them, they are a valued part of the organization. Happy employees are always going to work harder and step up when help is needed. If we look at the facilities around the US that had the lowest covid rates, I will guarantee you that they higher staffing ratios, longevity at all levels of staff and management that takes an active roll in the facility.

Instead of allowing CMS to guess how to make improvements in the future, CMS needs to work with the facilities around the country that stand above the rest.

CMS needs a better understanding of what truly goes on inside of LTCF. Many times, over the past few years when Evan Schulman, the Director, Division of Nursing Homes has spoken publicly on behalf of CMS you can tell that CMS did not have a good understanding of what residents have been through. CMS issues guidance often that is not clear and concise causing both surveyors and facilities to unsure how to implement the guidance. When CMS issues guidance late on Friday afternoon that is effective immediately, they are effectively saying figure this out on your own.

We need to make sure the mistakes of the past are never repeated. Covid taught us that shared rooms can be a death sentence when dealing with highly contagious diseases. Congress needs to provide adequate funding to make sure facilities can provide private rooms for all residents. When a facility is looking to expand, remodel and or relocate they need to be required to provide private rooms for all residents.

The survey system that is currently in place is a failure. Facilities are allowed to operate and provide care even when they have been cited multiple times for life-threatening violations. What it takes for a facility to be held accountable is unacceptable. When a facility is cited for a serious violation that puts a resident's life at risk there should have automatic consequences, mandatory education, and follow-up from the state survey department.

Residents, family members, advocates, and ombudsman often file complaints only be told that the surveyor didn't find any violations. True investigations are rarely done properly. Residents are often told

that there is no way to prove their complaints and that there is nothing that can be done. I had one resident tell me that he filed a complaint after a CNA left him half-dressed in his wheelchair for hours and because the surveyor wasn't there at that moment to witness it, there was nothing that can be done.

Even if a facility is cited, they are often fined such small amounts that they would rather just pay the fine they deal with the issues at hand. The survey system needs to hold bad operators accountable and rewards those doing a good job. Surveys are supposed to be done randomly but, most facilities know approximately when the inspectors are coming in and call-in extra staff and put on a good show. The number of residents that are interviewed needs to be increased. Instead of spending three or four consecutive days in a facility, they need to do their survey over a few weeks. Then returning unannounced to get a better idea of how a facility is operating.

As CMS oversees the surveyors there needs to be a better system in place when anyone has an issue with how the investigation was conducted. CMS need to implement a system that communicates with concerned parties when they file complaint regarding the state surveyors. Many times, calls, emails and letters sent to CMS go unanswered and or no resolution is shared with the concerned parties.

Families are an essential part of the resident's care team and should be treated as such. Residents must be allowed to have access to their essential caregiver 24/7, we have learned over the past few years how vital this is to the resident's quality of life. Residents depend on their essential caregivers to provide care that facilities don't have the time or staff to provide. Essential caregivers provide emotional, physical, and spiritual care while assisting with activities of daily living.

H.R. 3733 The Essential Caregivers Act was introduced to Congress in June of 2021. H.R.3733 will ensure that residents always have access to their Essential Caregiver regardless of the health emergency. H.R.3733 addresses safety issues to ensure that Essential Caregivers will follow the follow the same guidelines as staff members and gives facilities the means to terminate an Essential Caregivers access if they do not follow the rules.

As the population lives longer, more people are going to require some form of LTC. We need Congress to prioritize LTC to ensure that when someone needs care, they are receiving high-quality resident-centered care in a safe appropriate setting.