

Congressman Clyburn, distinguished members of the subcommittee, congressional staff, and guests,

Thank you for allowing the opportunity to share experiences with long term care facilities during the Covid pandemic. Nursing homes and other long term care facilities are close to my heart, and I think we can all agree that residents who live there deserve the best quality of life possible.

A quick background...My (active-duty) husband and I have 4 children, and our oldest is a 15-year-old boy who is a resident of a pediatric federally funded Intermediate Care Facility (ICF). He was randomly born with a host of complex, dynamic, and pervasive medical conditions, which have created varying forms of disability throughout the years. After several Tricare, Tricare ECHO, and state of Florida-waiver denials for in-home nursing care and/or respite care, we were left with little choice other than to look for a residential placement for him. He has been an ICF resident since 2014, and generally thrived pre-pandemic, as his dad and I were (and are now back) with him essentially daily since his placement at his facility.

I do realize this is a bit different from a more traditional nursing home stories, but while small differences among the various types of long-term care facilities or populations exist, the common theme is they all house vulnerable and fragile humans. It is also important to note that families have always been a part of these environments. I have spent the last 8 years personally and professionally invested in seeing the best for my son and every other human who is considered a Resident.

As you can imagine, COVID protocols including bans on family members, other advocacy and protection personnel, ombudsmen, and state surveyors; coupled with mandated 10–14 day quarantining periods were devastating to every human in all types of long-term care settings. Further, those who survived long term care during the pandemic, came out of it as “a shell” of their former selves. My son, like many others, too experienced significant regression both physically and psychosocially.

The inhumanity faced by children with complex medical needs and disabilities – already incapable of returning to their family homes pre-pandemic – cannot be understated. My son’s facility completely excluded parents and guardians from the building from March 2020 – Dec 2020, and from March 2020 – Aug/Sept 2020 we were completely banned from interacting with him in person. To reiterate, for 5 months (some families had to wait longer because of mass unit quarantines), my husband and I were not allowed to see/hug or hold our son in person for whom we still were legal guardians with responsibilities to him. We could only visit him through a window – can you imagine? We then cycled through a host of variations of predesignated 30 min/day, M-F, outdoor, and eventually indoor appointments in Dec 2020. Which again, to be clear, we had to make a 30-minute prescheduled appointment for our child; even after being vaccinated, while direct care staff did not. My husband, because of his employment, was fully vaccinated months before his facilities staff were mandated, alas it didn’t matter because he was only a ‘visitor’, a parent of a resident. Then around Dec 2021 – Jan 2022, parents and guardians were finally able to preschedule time-limited interactions with a resident in their bedroom. At present, we can access our son’s rooms and throughout the building without controls, but still must be granted access into the building. The fact that parent or guardians cannot independently walk into the building, represents a restriction in accessing the resident and removes the ability to randomly check-in to ensure residents are free of abuse or neglect.

The blind adoption of nursing home guidelines which were meant for adult and gerontologic populations by pediatric ICFs or nursing homes discounted everything we know about age-appropriate

care and treatment. Isolation policies designed by Centers for Medicare and Medicaid Services (CMS) for typical geriatric populations were imposed overnight on children who legally, developmentally, or medically could not advocate for themselves. It must be acknowledged that in early stages of the pandemic, seniors in nursing homes were dying but this was not the case with children. Early in the pandemic, even unvaccinated children with severe medical complexities, were not dying at anywhere near the same rates of COVID-19. Youth itself was protective, yet was completely disregarded in real time by CMS and all subordinate federal and state agencies who would point to CMS' nursing home guidelines and refuse to address children like mine.

Complicating this were inexperienced and/or underqualified facility administrators making decisions with state agency's support that clearly violated the basic rights/dignities afforded to a child or adult with or without disabilities in residential care, particularly ones who cannot talk. Some states bucked this trend and decided that residents of long-term care facilities could not and should not go without access to a loved one during the pandemic. Unfortunately, Virginia chose not to pass person-centered legislation and relied exclusively on promoting their interpretation of federal guidelines, even when these failed to address long term care subpopulations like children. This is more than my opinion, as I have served on the Virginia governor's long term care task force from September 2020 to the present.

Some may ask, "why spend time focusing on what happened, you can have access to your son now, let's move on." I will respond by quoting the philosopher George Santayana who said, "those who cannot remember the past are condemned to repeat it." Further, this hearing is evidence that we as a democratic society embrace citizen experience, find merit in the understanding how our society can learn from mistakes, do better for the most vulnerable among us.

During the early and current COVID periods, families and guardians became codified as 'visitors', reversing decades of partnership and putting facilities and families at odds. It was clear that the long-term care industry was and still is promoting a need for suspending of resident's right and projecting a limited view of infection control, while openly bypassing a person- or family-centered approach required by law, pre-Covid. We are still dealing with this phenomenon.

One of the central consequences of 'visitor' bans in pediatric long term care settings, arguably any long-term setting, is increased risk for abuse and neglect via decreased accountability. I would like to think this represents the minority of resident/staff interactions; but when it did, neglect and abuse largely remained hidden from families, except when dedicated staff members became whistleblowers. Facilities in Virginia are responsible for investigating themselves for concerns of resident's abuse or neglect. It does not take an attorney to realize the inherent conflict of interest in this situation. Fortunately, at my son's facility there were a few direct care staff members who witnessed maltreatment they could not live with and came forward, speaking truth to power. In fact, my husband and I were able to prove one of our son's neglect cases before the state, because a staff member stepped forward and contacted me directly to tell me what happened to my child. For reference, in the 5 ½ years pre-COVID, our child never was the recipient of abuse or neglect (outside of a few medication errors, which is considered medical neglect).

Staffing has been and still is an ongoing issue, as most of you already know. What I have witnessed is most of the good, caring, and qualified staff left during the pandemic. Many left due to the treatment of residents and the corruption of their work environments, not work demands or vaccine requirements. Many have expressed to me directly, even in this post-COVID setting, their deep conflicts with leaving

the children, because they love them so much, yet must take care of themselves, first. And I completely understand. Their replacement staff are less qualified, have little or no experience with families, and have workloads that never would have been allowed pre-pandemic. Their pay is insufficient in contrast to their responsibilities, making a position in long-term care less than desirable. In this post-COVID world where staffing is so poor that few staff are fired for things that would have been easy firing pre COVID. This leads to more egregious forms of abuse and neglect because maladapted staff in a pre-COVID world would have been weeded out in natural pruning processes. It seems that the fear of staff shortages has created situations where the need and rights of residents become secondary to the facility's need to protect itself.

Another example regarding this is a resident, who is a wheelchair-bound resident at the same facility. This child was punched in the stomach by a staff member who then threatened her fellow staff members not to say anything. The staff who ended up reporting the incident delayed a few days, because she was afraid of retaliation both directly from the abuser and professionally, yet she still decided to say something. Then, the facility fired her because she did not report the abuse soon enough, even though the retaliation she was afraid of occurred anyway. This was its own form of abuse against staff members. Recently even, there were quite a few ex-employees that posted online reviews of my son's facility. These reviews, like any which are subject to a selection bias, still pointed to systematic retaliation against people who spoke up for the children or refused to be harassed by fellow coworkers. I'll add, this has occurred since families have been able to return to the residents' rooms.

In concert with aforementioned 'visitor' bans, facilities are routinely behaving with a self-preservation mindset which has resulted in the follow behaviors: unwillingness to investigate suspected abuse or neglect, covering up abuse and neglect, not returning investigative reports within state specified time frames, showing preference to children without involved families, delaying or denying services such as speech or physical therapy, implicitly threatening placement of the resident, refusal to communicate with parents/legal guardians, taking parent of resident to court to garner additional funds from them, and other aggressive actions. These are current examples of the 'post-COVID' environment.

My son's facility receives just below \$900 daily to care for my son in addition to other medical expenses. This represents near the top of the federal reimbursement pay scheme, essentially one of Medicaid's highest paid facilities. This rate increased twice during the pandemic yet little to no services were being increase for the residents. I am aware that the facility has recently been investigated for Medicaid fraud after families voiced concerns their children were not receiving the benefits that Medicaid was being billed for. These are active examples.

As a point of interest, the direct care staff were also given a raise, but this was to catch up to the state's minimum wage. Can you wonder why there are hiring challenges? If I just graduated high school and could work for Amazon or have to lift, clean, and feed an 80-pound child- what should I do? And still, my son's facility refuses to stop admissions, even when it is clear the care suffers.

Just a few months ago, many parents brought this up at a family forum. We expressed concerns that the children were not getting access to the community, therapies, and were lying in bed for an inappropriate amount of time. We were met with a ubiquitous staffing shortage excuse. Yet, in the same conversation, when asked why the facility was not stopping admissions, they stated they would never do that. How can they be allowed to bring in new residents when they know they are not able to keep

with the needs of the current residents? These two phenomena are mutually exclusive, and represent ongoing issues.

As indicated Virginia did not lead the way regarding person centered care. In fact, the Commonwealth of Virginia was sued by the Department of Justice in 2012 regarding the state-supported practice of placing individuals with disabilities in long term care settings, particularly state-run facilities, while not providing appropriate and comprehensive community-based support services. My husband and I recently met with a DOJ-mandated community support liaison to inquire about the number of nursing care hours we could get to remove our child from the facility and into our home. She told us that she couldn't tell us that number. She suggested that we call a state licensed nursing agency, ask them to meet us at our house with our son present, and complete an evaluation to see what they would say. What is the point of her job if she can't even answer basic questions like what actual services, he would receive in-home? My son is tracked by this individual as required by the DOJ because of the 2012 suit, and personally, I feel like this should not have been a hard ask. I personally know of another family who has been requesting to remove their child with state supported resources, to which she is entitled. It has been nearly 8 months and she still doesn't have a date to take her child out. These are specific to Virginia, but I can't believe this is the way the ADA authors intended the system to operate or protect vulnerable long-term care populations.

COVID has been extremely difficult on our great nation, with nearly 1.05 million deaths-many of them among residents of long-term care facilities, with 350 deaths still occurring daily. My son's experience has shaken the very foundation of how I view the United States. If this can happen to him being an always vulnerable human, then it can happen to anyone. But, I must believe the country that I was born in, that we serve, and call home can do better than what happened. Long term care suffered in many international settings as well, but the United States had the resources and the capacity to be compassionate even in tough situations, and that's really what was lacking.

Several months into the pandemic, families from all over the country voiced concerns as elderly family members continued to die in mass in long term care settings. We were ignored because we were 'just' family, or in facility speak – a “visitor” – without trade group backing or lobbyists. The long-term care industry has significant federal and state lobbying power, and promoted itself as the experts of humans in residential care. But, could you ever tell a parent, guardian, or family member that they are not the expert on their love one? Of course not.

Decades of advocacy from both residents and their families have forced this industry to become better environments than they were historically. This stage of the pandemic is no different. This industry will continue to operate as it wishes unless residents, when able, and families who have witnessed what has happened, step forward and **say something because we all have seen something**.

My family lost time with a child who is on borrowed time already, and it seems as if in the post COVID world, the long-term care facilities and state agencies want us to be okay with what happened. I am not. Never in my lifetime did I expect to see such egregious violations of human and resident rights.

In 1963, Dr. Martin Luther King said, “Injustice anywhere is a threat to justice everywhere.” He goes on to say “Anyone who lives inside the United States can never be considered an outsider anywhere within its bounds.” Residents of nursing homes are not outsiders. Parents, families, and legal guardians are not outsiders. None of us are outsiders.

In closing today, I ask that you take my account to heart and turn emotion to action. Take up bills that protect the rights of long-term care residents, especially during a pandemic. Pressure CMS to create special policies for children in long term care settings, as these population are growing at exponential rates. And, most importantly imbue our great country with tangible signs of life, liberty, and the pursuit of happiness for all her citizens and others with in her borders.

With the highest respect and admiration,

Crystal Ton, MA, MPH