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My 40 year old daughter is slowly dying of Huntington's Disease. Since March 2016 she has resided in the Ferncliff Nursing Home in Rhinebeck NY in its Center of Excellence For Neurodegenerative Diseases program. Ferncliff is one of three nursing homes in NY with this program. The last time I hugged her was March 8, 2020. Before COVID I was there about eight hours a week, washing her face, brushing her teeth, cleaning her room, cutting her food, taking her outside, and loving her as fathers do.

Thousands of caregivers, like myself, are asking to return to normal visitation at nursing homes immediately after the residents have been vaccinated against the COVID-19 virus. The Department of Health revised visitation rules of February 22, 2021 do not achieve this goal. We also seek a permanent law so that a similar excessive lockout of caregivers does not reoccur. While S614B/A1052B seeks to address this concern, it needs significant improvement in order to actually achieve this goal.

My analysis of the Bill is set forth in detail in the appendix followed by a brief Bio. Let me summarize. We are faced with the need to balance the continuum of State police power to protect the public with individual liberty rights. This guidance must be set forth in the Bill:

When the risk of infection to a resident is no greater than the risk imposed by the staff of the nursing home, the resident's liberty right to free and unimpeded access by an essential caregiver is paramount.

1. Every resident must have an unqualified right to appoint an Essential Caregiver without the need for a medical opinion,
2. Excessive delegation of authority to the Department of Health,
3. Social distance completely undermines the ability of the Essential Caregiver to function,
4. Medical tests are not free or covered by insurance,

Respectfully submitted,

*Alan A. Pfeffer*

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Appendix  
Analysis of S614B/A1052B

## Guiding principle for Visitation During An Epidemic or Pandemic

When the risk of infection to a resident is no greater than the risk imposed by the staff of the nursing home, the resident's right to free and unimpeded access by an essential caregiver is paramount.

This principal must be set forth in the Bill

## Summary

The ability to have an essential care giver may be dependent on a medical opinion that maybe expensive, or impossible to obtain.

Excessive authority to regulate is granted to the Department of Health.

The continuation of social distancing precludes the purpose of having an Essential Caregiver.

Visitation may be dependent on expensive medical testing of the Essential Caregiver.

## Analysis

A. The Bill provides that the enabling regulations include:

.."procedures for the designation of personal care visitors by residents and legal representatives including requiring a medical or mental health professional to make a determination that such personal care visitor is necessary. Such determination may be made by a medical or mental health professional not affiliated with a nursing home or residential health care facility"

This above provision does not work and is unnecessary because:

1. Every resident must have an unqualified right to appoint an Essential Person, During the COVID 19 pandemic, unaffiliated medical personal were prohibited from entering nursing homes,

2. Who will pay for this medical service? There is no corresponding amendment of the Medicaid law or the Insurance Law to permit payment to the medical professional, An extensive review of the patient's record will be required, it is expensive and time consuming and will delay access,

3. It is unlikely that a medical professional will render an opinion in the absence of seeing the patient and rendering such an opinion without seeing the patient may violate medical ethics,

4. Our medical system has a history of race discrimination. See New York Times December 23, 2020 report on the experience of Dr. Susan Moore. Dr. Moore was a COVID-19 hospital patient who complained that her treating Doctor downplayed her complaints of pain. She expressed that this was a race based decision by her doctor. Unfortunately, Dr. Moore died of COVID-19. We cannot chance the potential entry of discriminatory practices in to the determination of the need for an Essential Person, and

5. We should not assume that every resident had a personal physician prior to entry into the facility who can easily render the needed opinion. People on Medicaid and people who relied on hospital emergency rooms as his or her primary care physician or community clinics often do not have prior personal physicians, and This language potentially may be used by facilities to exclude visitors who the facility feels complains to much about the care their loved one receives.

B. The Bill authorizes the Department of Health to issue regulations. While this is the usual method of implementing a law it is ill-suited for the following reasons:

1. It will most likely take a year to issue final regulations. It is a long process. Regulations lack flexibility. The COVID-19 pandemic has demonstrated the need to act quickly and under changing circumstances. As events change and unfold Government needs maximum flexibility to change the rules.

2. The Bill grants excessive authority to the Department of Health. The Bill should set forth the rules with minimum interpretation left to an agency via guidance .

C. The Bill provides authority for the Department of Health to :

“require, at a minimum, that all personal care visitors follow safety protocols required for nursing homes and residential health care facilities' staff, including, but not limited to:

- (i) testing for communicable diseases;
- (ii) checking body temperature;
- (iii) health screenings;
- (iv) the appropriate use of personal protection equipment;
- (v) social distancing; and
- (vi) any other requirement the department deems appropriate;
- (i) set forth frequency of visitation and duration of visits by personal care visitors at nursing homes and residential health care facilities; and
- (j) set forth the total number of personal care visitors allowed to visit a nursing home or residential health care facility at any one time”

Objections to the grant of authority are:

1.It is open ended and the Department of Health can add additional criteria.

2.Who will pay for the testing for communicable diseases? Under existing Insurance Law, and Medicaid law, neither a health insurance policy nor Medicaid will pay for a test for the sole purpose of gaining entrance into a nursing home as a visitor. In the absence of a doctor's order, symptoms, or being an essential worker, an individual who needed to be tested for the COVID-19 illnesses for the purpose of complying with the rules on limited visitation was required to be tested within 7 days of each visit at either his/her own expense or at one of the limited free sites set up by NYS. There is no guarantee that such free State sites will continue.

3. Social distancing completely undermines the purpose of having an essential caregiver. A resident cannot be helped to eat, or be washed if distancing is required.

4. There must be no limit on the frequency or duration of visits. At least one nursing home has limited its visitation hours under current State guidelines to three days a week with no night time visits. An Essential Caregiver who works during the day on weekdays would be precluded from visitation at this facility unless he or she takes time off from work.

5. The grant of power to impose any other requirements deemed appropriate is overly broad and must be removed.

6. Every resident must have the right to a personal care visitor that is not subject to limitations based on the number of other visitors.

C. To the extent that the above provisions are also set forth in the compassionate care visitation portion of the Bill, the objections are equally applicable to those provisions.

## BIO

My name is Alan A. Pfeffer. My daughter, Charise, age 40 has Huntington's Disease. HD is genetically caused. You can only inherit it from a parent and the risk of inheriting it is 50%. Her Mom, my first wife, had it. The mutant protein produced by the defective gene slowly kills brain cells and nerve synapses. As the brain slowly dies the individual loses all their abilities. There are no treatments, no cures, and no survivors.

Since March of 2016 Charise has resided at the Ferncliff Nursing Home. Ferncliff has a specialized program for HD and ALS known as Centers of Excellence for Neurodegenerative Diseases. The program was authorized by the Governor in Sept 2014 after a three year advocacy effort that I led. To help create the details of the program the NYS Department of Health had a two year advisory committee. I was on that Committee. I was the only person on it that represented the "consumer".

I have a history of advocacy on behalf of people with HD. I successfully advocated for the inclusion of HD as one of only ten illness eligible for medical marijuana in the original legislation. I have testified twice before the NYS Assembly, on Single Payer health care, and Medical Aid in Dying. The latter was by invitation. I have advocated for an expanded version of medical aid in dying so as to provide the same end of life right of choice to more people than intended by the program in the several States that have it. Toward that goal, I was granted permission to file an Amicus Brief before the NY Court of Appeals when the issue of MAID was before the Court.

Last year I testified before the State Medicaid Re-design team and submitted comments to that body intended to protect the Centers of Excellence program from Budget cuts. I have met several times with Staff of Governor Cuomo's office and regularly submit information to them.

I am the Advocacy Chair of the Albany NY Chapter of the Huntington's Disease Society of America. I regularly do public education and twice a year I do police training related to Crisis Intervention. I was able to get the NY State Trooper training program to include HD and that led to a change in the National Police training materials.

I am a retired attorney. For most of my career I was employed by NYS. Among my many duties I served as the head of the unit that defended the State from Federal Disallowances in the Medicaid, Food Stamp, Foster Care and the old AFDC program. I did administrative appeals before the DHHS Departmental Appeals Board and a similar Board for the Food Stamp program. Beside formal appeals, I negotiated regularly with Federal Officials, commented on proposed federal regulations, and advised the Governor's Office and Department officials on federal policy. On a few occasions I negotiated legislation with members of Congress and successfully achieved a change in the Food Stamp program. For disallowance court appeals I worked with the State Attorney General's Office for cases brought in the Federal courts. I wrote several Briefs for the federal District Court and Circuit Court of Appeals and assisted in the preparation of one Amicus Brief brought by a coalition of States before the U.S. Supreme Court.

I started my legal career as a Legislative Aid in 1972 and in 1975 I was Counsel to Senator Jack E. Bronston.