

STATE WIDE

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Convened by:

New York State Senate Committee on Health,
Senate Committee on Aging,
Senate Committee on Investigations and Government Operations,
Assembly Committee on Health,
Assembly Standing Committee on Aging,
Assembly Committee on Oversight, Analysis and Investigation

Thank you for your leadership in holding these hearings and for the opportunity for input. I serve as the Coordinator of the Patient Advocates program for NYSWAC. Before joining StateWide that I served as a Deputy Director at the NYSOFA among my duties at that time was the coordination of disaster planning and recovery operations for the aging network. I appreciate the opportunity to provide input to your important hearings.

StateWide is a 48 year-old organization governed by senior citizens. We operate a Patients Rights Helpline 800-333-4374 that assists patients, families, and Medicare beneficiaries with patients rights issues, suspected fraud, and Medicare benefits issues. We are also the lead agency for CMS in New York State for the Medicaid and Medicare Fraud Prevention program known as Senior Medicare Patrol.

With the limited time today I will stress a couple recommendations:

Patients Rights

Just as is the case with the citizens knowledge about rights like access to long term care ombudsmen, most people do not know that there is a patients bill of rights. Waiting until someone is in the hospital to educate them about patients rights is too late. The process needs to begin in the community. We suggest that the state agencies form a collective to provide education about patients rights in the community for caregivers rights utilizing local community based organizations who are trusted by the most vulnerable populations. Information about patients rights then needs to be reinforced at the time of admission.

The pre-COVID pandemic play book called for the suspension of many patient and human rights in order to sustain the health of the general public. In the post COVID era we know that the suspension of many of those rights is really counter productive especially as they relate to the care of the elderly.

Rights removed included provision of a copy of the medical record; patient visitation; and seclusion. Hospitals no longer need to explain to a patient or a patient's family member why a decision has been made to remove them from a bed. Yet a pandemic is probably the time when the patients bill of rights is even more essential. It is a time when the ability of patients and their family members and advocates is totally compromised.

Learning from our experience we now know that providing medical records is critical in helping patients and families understand their care history and make critical health decisions. Family visitation can be very helpful in the process of patient recovery if done safely. Hospitals now know how to do this. No one should be without some social contact. New York should convene a group of consumer and hospital representatives to develop pandemic visitation protocols and policies that could be built into state, local, and hospital pandemic plans.

Communications with families is paramount.

-Multicultural and non-English speaking families need to be provided with information they can understand. Materials must be translated into languages consistent with the communities in need - not just English and Spanish.

-The hand off from ambulance to hospital is often the first leg of a disorienting journey. Therefore, the state should establish a tracker system for patient information. Too many patients were treated without the family knowing which hospital they had been admitted to, patients died unidentified, families could not find loved ones for weeks, only to find that they had died. To keep families informed as to which facility the patient is taken to.

-The state needs to revise compassionate care visitation rules for visitation at end of life.

-The Executive order that allowed partner to be in labor & delivery - that was good, but the elderly also needed an essential visitor.

-The religious views of the patient must be honored , even during a pandemic.

-During last rights, the Jewish ritual of watching over the body of a deceased person from the time of death until burial should be honored.

-There needs to be education in the community and caregivers of patients rights utilizing local community based organizations who are trusted by the most vulnerable populations.

Discharge planning

Older persons, on average, use five times more acute care than other adults. That's not surprising because many have multiple chronic conditions.

In recent years, admission and reimbursement policies have created a scenario where patients are discharged on a quicker and sicker basis. After acute treatment the discharge process becomes another critical decision point and moment in the care career of the patient and often determines if they transition to better health or end up being readmitted.

Thus, under normal circumstances the quality of hospitals' discharge planning system becomes absolutely critical to older persons and their families.

But COVID was not normal circumstances and during COVID older persons have been disproportionately infected and killed.

At a time when patients and families desperately needed the best discharge planning possible government instead waived many of those services.

Discharge planning is an essential component of a good health care system and not merely a process to move a patient from one level of care to another due to insurance coverage limitations that limit the number of days of treatment in a hospital or home health agency setting.

Many of you may be aware that the federal government recently updated and improved discharge planning regulations. However, under the COVID-19 Emergency Declaration Blanket Waivers for Health Care Providers During the pandemic CMS waived: "...all the requirements and sub parts at 42 CFR §482.43(c) related to post-acute care services so as to expedite the safe discharge and movement of patients among care settings, and to be responsive to fluid situations in various areas of the country."

This removed many of the many improvements recently made to the federal discharge planning regulations.

While many of the waivers provided to hospitals during the COVID epidemic were helpful, we believe that it is important to re-institute all federal and state discharge planning requirements.

This includes new rules that require that discharge planners:

- engage the families and patients in developing care plans that meet their preferences;
- provide information about providers such as long term care, rehab or community based care so that they can make an informed decision about their care; and
- clarify for families and caregivers as to their freedom to pick a provider of their choice and of the Medicare coverage for any post acute care.

These rules should apply to patients regardless of whether they are being placed into observation status, are under emergency room care, or being formally admitted.

As part of the checks and balances to assure a good discharge planning process and high quality of care, the discharge process should inform patients and families of their rights to appeal their discharge or complain about quality. It is important to inform patients and

caregivers with contact information for discharge staff throughout the duration of patient care provided by a hospital so that patients and their caregivers can discuss any concerns about their discharge plan or changes in their care.

How will the state know if bad things are happening if there is no one to complain to? It is also important to inform patients of their rights to appeal a discharge or complain about quality of care they have received to the:

- Beneficiary and Family Centered Care Organization
- the State Department of Health's patient complaint line.
- The Attorney General's COVID complaint line.

This is particularly important since surveys from the Joint Commission were suspended during COVID.

Data about complaints made to the Quality Improvement Organizations and DoH is opaque to the public. The state legislature should demand that DoH do an analysis of complaints made during COVID to identify the types of concerns and the corrective actions taken and determine if there are facility or region specific patterns that need to be addressed. (This should be done on an ongoing basis after COVID so that we can improve the system. DoH should be asked to explain why they don't do it since they have the data.)

During COVID it is also critical that hospitals follow CMS discharge planning regulations recommendations help patients transition back into the community by connecting them with Aging and Disability Resource Centers, Area Agencies on Aging, and Independent Living Centers so they can obtain needed community services and supports.

These agencies are valuable resources at the community level. However, referring patients to these agencies does not absolve a hospital of their responsibility in helping them make needed connections for follow up services. Hospitals must share in the responsibility for not only helping identify post acute service options but also for linking patients to the option they have selected.

3 Day Hospitalization (and Observation Status) Requirements:

During the pandemic federal regulators recognized the barrier that the awful observation status policies have on the continuum of care. Using the authority under Section 1812(f) of the Act, CMS waived the requirement for a 3-day prior hospitalization for coverage of a SNF stay. This provided temporary emergency coverage of SNF services without a qualifying hospital stay, for those people who experience dislocations, or are otherwise affected by COVID-19.

In addition, for certain beneficiaries who recently exhausted their SNF benefits, it authorizes renewed SNF coverage without first having to start a new benefit period (this waiver will apply only for those beneficiaries who have been delayed or prevented by the emergency itself from commencing or completing the process of ending their current benefit period and renewing their SNF benefits that would have occurred under normal circumstances).

We recommend that New York seek to continue the waiver of this policy beyond the pandemic for Medicare beneficiaries. This will allow a smooth and lasting transition out of the hospital to needed post acute rehabilitation. We also suggest that the state work to require that Medicare and Medicaid Managed Care Providers in New York provide coverage of rehab in a skilled nursing facility when they are discharged from a hospital if they are medically needy of such care, and especially if they have had 3 mid nights in a hospital regardless of whether they were in inpatient or observation status.

And of course we urge the legislature to work with the Congressional leadership to pass the Improving Access to Medicare Act. Which would use any time in a hospital to satisfy

the requirement.

A Wake Up Call for Better Health Care and Disaster Planning

COVID exposed many flaws in our hospital and disaster planning. We have now experienced more health crises in a shorter period of time over the past few years we must develop a plan for future pandemics now before the next catastrophe hits.

Over time there has also been an insidious drift away from community planning that is undermining the fabric of our hospital and health care system. Decisions are often made with input from the chosen few who often stand financially gain and often contribute to political campaigns. It's more convenient to work with them. They have lobbyists in Albany that seem to have unlimited access and are ready to help. They should have a voice, but so should the people whom they are being paid to serve, primarily with public dollars.

This type of planning and implementation culture has created a great blind spot that COVID-19 has exposed. That is why the governor quickly abandoned the old modus operandi and called upon hospitals to work together and share resources and planning instead of operating like competing islands. Its time to go back to the future. As we move ahead the legislature should ask....shouldn't this be the way it in the future as well.

The state needs to work hard to counter this imbalance of interests and to put the rights and needs of the public ahead of special interests.

Regional health and long term care planning input in New York ceased with the dismantling of the Health Systems Agencies and serious community based input has been eliminated in favor of top down inner circle planning and through the Public Health and Health Planning Council whose membership is dominated by executives of massive health providers and the insurance industry. More consumer membership is sorely needed on the Council and CON reviews need to be expanded to include reviews by the Attorney General's Office to review mergers, consolidations and sales of nursing homes and hospitals.

-Cease approving closures and mergers of hospitals

Prior to the pandemic, Community Voices for Health Systems Accountability and other groups were called for a cessation of hospital closures and mergers. Even during the pandemic the state moved ahead with giving approvals for more bed closures. This was obscene. The state needs to cease such actions and reassess every request in the new light of the needed pandemic capacity especially in undeserved neighborhoods.

Engage the Community In Health Care Planning

This is especially important in the new post pandemic era where we now realize how disproportionately impacted minority populations, low income and undeserved communities have fared. These populations and the community based organizations have been left out of this process yet they hold the key to assuring that in the future the communities of colors are not marginalized.

We also recognize the critical need to have a capacity of intensive care unit and hospital beds when a pandemic occurs.

Most states have had pandemic plans on the shelves for years– they were written but never tested and most never really focused much on people with functional needs or cultural differences.

The Committees that are coordinating these hearings need to provide the hearing recommendations to the state and the county and NYC disaster planning and recovery agencies to find out what they need to ensure that pandemic planning for functional needs populations are integrated into this framework.

-Residents, families and community based organizations need to be involved in developing pandemic plans.

Time and time again functional needs populations are not included in the actual design, testing and implementation of emergency response plans. This needs to change.

-Disaster Plans Should be Functions Based and Include a Whole Community Perspective

Part of the problem is that even forward planning disaster preparedness best practice documents offered little about pandemics. However, there are solid recommendations for overall planning that provide a great framework for inclusive future planning.

-Residents, families and community based organizations need to be involved in developing pandemic plans.

We know that low income, minority, undeserved communities, and persons with functional needs were disproportionality impacted. We need to make sure that care is provided according to need rather than expediency. Many safety net hospitals did not get the resources needed while patients languished in hallways and common areas and cafeterias acting as make shift wards while more affluent neighborhoods got resources quicker because they were better equipped to navigate the supply chain.

Therefore, it is even more critical to involve these segments of the population in health and disaster planning. The need to be included in the actual design, testing and implementation of emergency response plans.

-We need a special emphasis on planning for the needs of multi-cultural populations.

These groups have always been disproportionately impacted during disasters and it has been even worse during COVID-19. It is critical to recognize the need for an initiative to engage multicultural and limited English speaking populations in planning and through a warning and communication system that is sensitive to their needs and preferences. A model New York should explore is the Emergency,Community, Health Outreach and Emergency Response Services (ECHO) non-profit and government partnership program in Minnesota. They have developed multi-language television, social media programs, and other communication and outreach strategies that provide a process to connect with multi-cultural and Limited English speaking populations to rapidly and inform them during a disaster.

(<http://www.echominnesota.org/> <https://www.youtube.com/user/ECHOminnesota>)

-Disaster Plans Should be Functions Based and Include a Whole Community Perspective

Part of the problem is that even forward planning disaster preparedness best practice documents offered little about pandemics. However, there are solid recommendations for overall planning that provide a great framework from which approaches can be developed to assist functional needs groups during pandemic recovery in nursing homes, adult homes and assisted living centers.

New York can utilize and build off of the existing standards and guidance:

-The CDC has developed the Public Health Emergency Preparedness and Response Capabilities which established 15 capabilities that serve as national standards for public health preparedness planning.

(<https://www.cdc.gov/cpr/readiness/capabilities-change.htm>)

-New York, NJ and Connecticut have also developed recommendations on how to take a “functions based approach” with a “whole community” perspective. (See : “Promising Practices and a Guidebook with Support Tools for Access and Functional Needs Integration in Emergency Management January 31, 2015,New York-New Jersey-Connecticut-Pennsylvania Regional Catastrophic Planning Team.”

<https://crcog.org/wp-content/uploads/2017/12/Promising-Practices-and-a-Guidebook-for-Access-and-Functional-Needs-Integration-in-Emergency-Management.pdf>)

-The Capital Regional Council of Governments in Connecticut also offers an extensive functional needs inclusive planning library.

<https://crcog.org/public-safety/homeland-security/functional-needs-inclusive-planning-e-library/>

Note: FEMA suggests the use of the “whole community framework” which emphasizes the value in understanding and meeting the actual needs of the whole community, including those with disabilities and others with access and functional needs; engaging and empowering all parts of the community; and strengthening what works well in communities. A whole community perspective builds on the access and functional needs approach by identifying common functions that a jurisdiction must perform during emergencies to meet the needs of its whole population.

In closing we want to thank you for narrowing the waiver of liability for hospitals. The ability to register quality of care complaints and seek legal measures to address poor care are two very important critical parts of the system of checks and balances.

We have much to do to repair the problems talked about today and build a better system for the future. Let's create solutions and action rather than blame and excuses. We look forward to working with you to that end.