The complex case discharge delay problem

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Our system of care has a design flaw — it is primarily designed for people with a clear path, for those who do not have complex care needs upon discharge.

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Executive summary

A 12-year-old girl was admitted to a hospital in New York state with symptoms due to a traumatic brain injury and bipolar disorder. She was clinically stabilized and ready for discharge two weeks later, but when no safe discharge options could be found, she became stuck in an acute locked psychiatric setting for eight months.

Pleading for a placement, her hospital social worker wrote:

"She cries hysterically daily, begging for a discharge, and claiming she is forgotten in a psych ward ... she is tenacious, funny, loving, connects well with adults, has spirituality, a great sense of humor, and dreams for her future."

Hundreds of New Yorkers experience a similar fate each year: months-long hospital stays. Thousands more experience some kind of non-medically necessary discharge delay. Regardless of whether the delay is days, weeks or years long, there are risks and harm to patients who could otherwise be served at home, in the community or other less expensive care setting — without disrupting access to care for others. The time to confront this persistent challenge is long overdue. This paper provides a high-level examination of the complex case discharge delay problem in New York state and outlines a way forward.

Complex case discharge delays, also known as bed blocking or bed delays, are a longstanding, growing challenge throughout the U.S. and the world.[1, 2] These delays happen for many reasons, but are most commonly attributed to difficulty finding safe post-discharge care and lengthy administrative or legal processes. Individuals experiencing behavioral health, intellectual or developmental disabilities and/or co-occurring conditions are most profoundly impacted.

Once a person enters through emergency room doors, hospitals become responsible for their safe care and discharge.[3-5] As a result, people are often brought to the emergency department as a last resort — when no other options for care can be found. The unintended consequence is a system where hospitals are left bridging gaps between health and social care; serving as a long-term destination rather than as a way station for those who, once their acute care needs are met, are better served in a non-hospital setting.

Our system of care has a design flaw — it is primarily designed for people with a clear path, for those who do not have complex care needs upon discharge. There may not always be a perfect discharge setting for complex case patients. However, there is a shared responsibility to acknowledge this problem and find the perhaps imperfect but best possible solution. What we are doing now is a disservice to our communities and people who "live" in a hospital.

HANYS seeks to convene stakeholders, and offer expertise in setting policy while strengthening relationships and establishing best practices across the field to achieve better patient outcomes. The following actions will help patients and hospitals in the short term, and create the foundation for long-term solutions:

- build and maintain stakeholder dialogue to make New York best in class at solving complex discharge cases;
- establish a senior level, multi-agency response team for cases that should be escalated to commissioner level direction, with provider input;
- identify mechanisms to understand the extent and scope of this issue through a multi-system analysis;
- advocate for changes to regulations or advancement of legislation to remove barriers and create care models to address gaps in the care continuum;
- develop consistent behavioral rules and practices for county agencies, community-based providers and/or other stakeholders;
- form complex case discharge response teams in every hospital and health system;
- educate hospital staff about the full range of resources available; and
- identify clinical and administrative practice and process improvement strategies.

There is a shared responsibility to acknowledge this problem and find the perhaps imperfect but best possible solution.

Background

Our healthcare delivery system has undergone significant transformation to reduce unnecessary hospitalization; payers have developed payment models to incentivize providers; New York state has allocated billions of dollars to initiatives such as the Delivery System Reform Incentive Program;[6] and hospitals have formed partnerships, invested in population health and adopted tools like Lean and high reliability.[7-9] Despite these investments, patients with complex care needs continue to become stuck in EDs and inpatient units for weeks, months or years, with catastrophic ramifications.[10, 11]

In this paper, HANYS describes the unintended consequences of a system that does not "see" complex case patients, based on the experiences of hospitals and patients.

Unintended consequences

Patients

A lack of coordinated care options has created an environment where complex case patients needlessly languish in EDs and hospital beds.[12, 13] Evidence shows that unnecessary hospital stays can lead to an irreversible decline in functional status and negatively impact psychological well-being, especially for older adults and children.[14 - 18] Prolonged hospitalizations worsen these impacts in immeasurable ways.[19] Imagine the unconscionable experiences suffered by patients who live in limbo in the hospital environment. They lose their autonomy, become socially isolated and lack access to the intellectual and physical activity necessary to thrive.[20 - 22] Most families are left in turmoil; watching helplessly and wrestling with care options that undermine their own well-being.

These repercussions are most profound for individuals who are already struggling with disabilities and/or behavioral health disorders. Advances in science and investment into community programs have allowed individuals who were previously institutionalized to achieve higher levels of independence than ever before. Access to a stable environment, regular participation in therapy and the freedom to participate in social or physical activity is essential to achieving and maintaining this independence.

Imagine the unconscionable experiences suffered by patients who live in limbo for months to years in the hospital environment. They lose their autonomy, become socially isolated and lack access to the intellectual and physical activity necessary to thrive.

When patients become stuck in hospitals they are deprived of what they need to progress and often deteriorate. They often need more advanced care upon discharge than when they arrived.[23] Complex case patients with behavioral health disorders and/or intellectual and developmental disabilities are especially vulnerable because their conditions are also often poorly understood.

Hospitals have adapted to best meet the needs of patients, but they are expertly engineered to provide acute care in the short-term, and are not an acceptable place to live.

Care delivery

Bed shortages

Discharge delays limit access to beds for others who need hospital care, a critical problem highlighted most recently during the COVID-19 pandemic.[24, 25] Patients who may otherwise receive inpatient care in their local community may need to be diverted elsewhere. Further, bed shortages lead to ED boarding, a situation where patients are admitted to a hospital, but remain in the ED, often for days, until beds become available.[26] ED boarding contributes to ED overcrowding, which results in diversion and other negative repercussions on patient care.[24]

Staff grapple with moral distress ... they visit on their days off to celebrate birthdays and provide patients with fresh air.

Safety

Symptoms of certain behavioral health disorders or disabilities may cause individuals to be a danger to themselves or others. These patients often require one-to-one or two-to-one staff ratios. Outbursts or unusual behavior can also be distressing to patients and staff. One report indicated that 8% to 44% of patients in psychiatric units present with violent behavior during their stay, and 80% of staff have experienced aggressive behavior from patients.[27]

Staff well-being

Hospital staff often face an increased risk of injury, extended work hours and a disruption to their care environment. They are deeply impacted by prolonged discharge delays. Physicians, nurses, social workers and others grapple with moral distress when they are unable to provide adequate care to patients or solve problems largely out of their control.[28, 20] For example, hospitals noted that staff visit on their days off to celebrate birthdays and provide patients with fresh air.

One NYS hospital system estimated the average cost of care for the most complex patients to be $5,000 per day.

Cost

The unreimbursed costs associated with care for patients experiencing complex case discharge delays are extraordinary.[29] While we don't yet fully understand the magnitude of the cost in New York state, limited studies provide clues. A report from Maryland estimated that behavioral health discharge delays alone cost their hospitals $30 million annually.[12] An analysis conducted in Hawaii found more than 7,000 complex case patients, with an annual loss to hospitals of $60 million in 2011.[30] One New York state hospital system estimated the average cost of care for the most complex patients to be $5,000 per day, and that complex case delays often exceed 100 days.

Reasons for the high cost of care include:

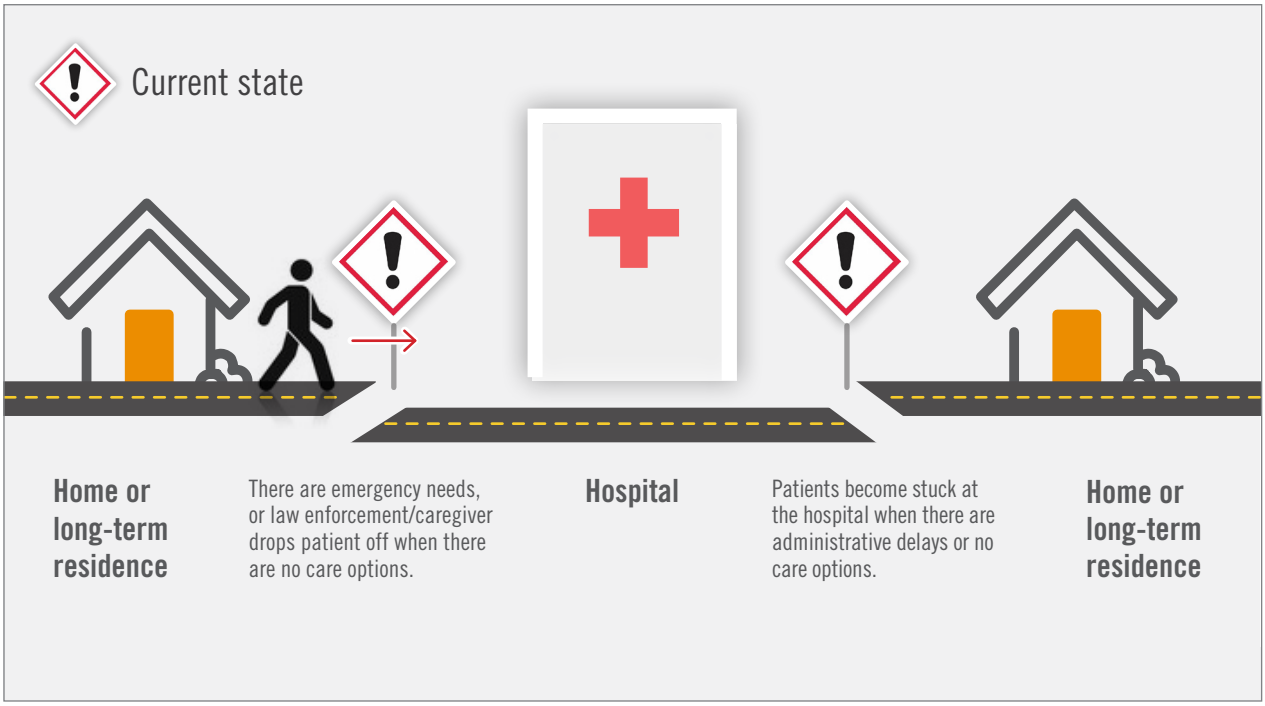
- additional specialty care and security staff;
- staff injuries, absenteeism and overtime;
- legal fees for guardianship and other administrative costs;
- multidisciplinary, advanced discharge planning; and
- loss of revenue due to lack of standard patient turnover for occupied beds.[31, 21]

Inadequate payment

Despite payment reform efforts, the current system continues to result in a convoluted scheme; ultimately denying care and adequate reimbursement. Rather than ensure that patients receive timely discharge and placement, insurers cease to pay for non-acute care or reimburse at an insufficient alternate rate, and present a dizzying maze of administrative obstacles. There is no incentive to streamline placement and assist with appropriate discharge. Furthermore, for patients with behavioral health needs, the continued disparity around payment parity remains — reimbursement rates for behavioral health services continue to lag behind.

Complex case patients do not fit neatly into any care model within the healthcare system because the system is not designed for them.

Gaps in the care continuum

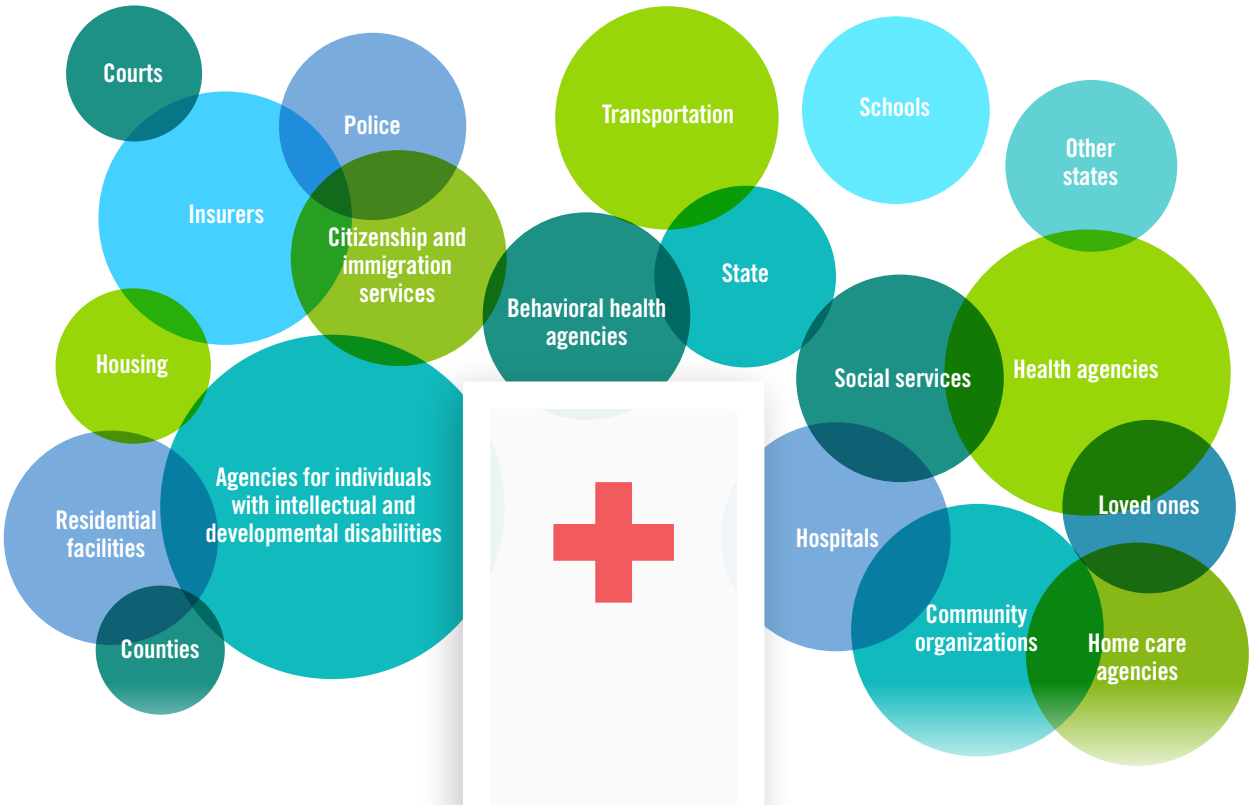


A system design flaw

Why patients get stuck

Complex case patients arrive at hospitals for emergency care or when authorities or loved ones believe there are no other safe care options. Under the Emergency Medical Treatment and Labor Act, hospitals are required to screen all individuals who come into the ED.[5] Once the hospital determines that a patient does not or no longer requires hospitalization, the facility is required to identify a safe discharge option.[3, 4, 32]; often a near-impossible task, tangled by a mire of administrative obstacles for the complex case.[33]

Hospitals may be required to work with more than 20 entities at the state, regional and local level to discharge a single complex case.



Entities hospitals work with to care for complex case patients (not all inclusive)

Patients often experience discharge delays due to a gridlock in administrative processes, outside of the hospital's control.

Not it

Complex case patients do not fit neatly into any care model within the healthcare system because the system is not designed for them. A game of "not it" begins when the hospital works to find an appropriate discharge setting. Hospitals spend a great deal of time searching for options, such as at-home support, skilled nursing facilities or residential facilities to meet the long- or short-term needs of patients after hospitalization.

Unfortunately, in many cases, patients do not meet post-acute care admission criteria perfectly, there is no bed available or loved ones aren't able to care for them. With every discharge attempt, the hospital is knocked back to the beginning and must restart the complicated process all over again.

EXAMPLES

- Many of the step-down facilities for mental health or substance use disorders are not able to manage medical or other behavioral health comorbidities and vice versa.[34]
- Post-acute services are often unable to care for children, patients with behavioral health disorders or criminal histories (e.g., sex offense) or patients recovering from infections.[35]
- Medication-assisted treatment is often unavailable to individuals who are incarcerated.[36]
- Patients or loved ones may refuse available post-acute care settings due to a desire to return home or wait until the preferred long-term care setting is available.

The steady closure of residential care beds in recent years is exacerbating this challenge, particularly for patients with behavioral health disorders. Since the 1950s, there have been increasing efforts to shift resources toward care of individuals in the community and away from institutionalization.[37 - 41] Many have benefited tremendously from these changes. However, in some areas of the state, the pace of community-based service expansion has yet to fully meet the demand.[42]

The growing number of individuals with serious behavioral health disorders in New York state is increasing the demand for these limited services.[43]

EXAMPLES

- The Office of Mental Health is closing inpatient beds within its psychiatric centers as part of its Transformation Plan.[42]
- Hospitals have been forced to close units or reduce psychiatric beds because reimbursement rates for behavioral health services are far below the cost of providing care.

Administrative obstacles

In addition to limited post-discharge care options, patients experience discharge delays because of a gridlock in administrative processes, often outside of the hospital's control. Hospitals must untangle an inordinate web of rules and protocols to help these patients transition home or to a post-acute setting. Administrative delays are largely attributed to governmental processes, insurance authorization, guardianship, court-ordered treatment and internal hospital coordination.

Government policies and protocols

Despite efforts to integrate services through state agencies (OMH, Office for People With Developmental Disabilities, Office of Addiction Services and Supports and Department of Health), hospitals believe more coordination is needed. Each agency owns criteria for eligibility, services, treatment plans and protocols.

When the hospital seeks assistance from the state, it may be required to interact with multiple state agencies for a single patient — DOH, OMH, OASAS and OPWDD, and often the State Education Department and court system. For example, when presented with a complex case such as an adolescent with traumatic injury and bipolar disorder, who ultimately decides which setting is best suited for the patient? Efforts to address this problem have been inadequate and patients continue to become stuck.

Insurance authorization

Most complex case patients require ongoing care at home or in a long-term care setting. Patients must be insured or pay for this care directly for the post-acute care setting to accept them. The process of receiving authorization from insurers and/or applying for insurance to cover post-acute care is lengthy and complicated.[33, 44, 45] Consequently, hospitals take on this burden. This process becomes even more nuanced for patients who are undocumented immigrants.

Regardless of immigration status, in New York state, children are eligible for Child Health Plus and certain adults may access Medicaid for emergency services. However, if a patient is not eligible for insurance, the hospital then becomes responsible for ongoing care.

Guardianship

When a patient is unable to make decisions, a guardian is assigned to grant consent for the patient to be discharged to another setting.[46 - 48] If a guardian is not easily identified, a search begins to find a loved one willing to become the guardian. If no loved ones are identified, the hospital is left to petition the court for guardianship and becomes burdened with many legal and administrative costs.[49]

Guardianship is critical to protecting the rights of individuals who are incapacitated in these situations. However, the process as it exists results in extended discharge delays that are harmful to patients and hospitals.[50]

Court-ordered treatment

Individuals may be involuntarily committed to inpatient psychiatric care or required to participate in outpatient treatment by court order.[51, 52] There are often delays due to objections or appeals.[53]

Like guardianship, the appeals process is critically important, but delays in the process result in patients being stuck in the hospital, and sometimes, delayed treatment.

Advanced care planning

Decisions for advanced care planning, or planning regarding a patient's care values and preferences for care, can also lead to unnecessary hospitalizations and discharge delays.[54] The process of identifying surrogate decision makers and engaging in advance care planning conversations for individuals who experience cognitive impairment can be lengthy and requires the involvement of clinical staff and government agencies.[55, 56]

Internal hospital policies and protocols

The most severe delays happen for reasons outside of hospitals' control. However, some unnecessary delays can be caused by processes for implementing a care plan or referral. Gaps in knowledge about protocols for facilitating the discharge of a complex case patient may also contribute to delays. This challenge is aggravated when the response or process for responding to a case with oversight agencies is inconsistent.

Our goal is to lead efforts to identify systemic and practical solutions to ensure patients are not living in a hospital.

Attempts to address the challenge

The complex discharge delay problem directly impedes efforts to optimize care delivery and achieve the "Quadruple Aim" of better care, better health, lower cost and staff satisfaction.[57 - 59] A growing number of groups have been working to acknowledge, understand and offer creative solutions. A few examples are highlighted in this paper.

Other countries

The National Health Service, England and Canada, are undergoing extensive efforts to address complex case discharge delays.[60, 61] The NHS issued the Community Care Delayed Discharges Act in 2003, which aimed to reduce discharge delays through financial incentives for social service agencies.[62] Patients with complex care needs are also folded into the NHS plan used to communicate national healthcare goals every 10 years.[63]

The United States

The Institute for Healthcare Improvement has developed a blueprint and playbook dedicated to improving care for people with complex care needs.[64] Two other state hospital associations, in Maryland and Minnesota, issued reports on discharge delays related to behavioral health conditions.[12, 13]

New York state

Hospitals

Hospitals across New York are developing strategies to proactively address complex case discharge delays.[65] Several have built interdisciplinary teams that meet regularly to problem-solve. These teams bring together medical staff, social workers, psychiatry and behavioral health, ethics, discharge planning, legal and others to identify the obstacles preventing a safe discharge and work together to remove them.

Beyond managing medical and behavioral health challenges, these teams are responsible for tackling the plethora of situations that result in discharge delays. This type of team requires significant commitment from hospital leadership, as well as functional relationships with many stakeholder groups outside the hospital, especially state agencies responsible for these populations. Most hospitals cannot take on efforts in this way due to resource limitations and the diverse nature of relationships with stakeholders.

Our goal is to lead efforts to identify systemic and practical solutions to ensure patients are not living in a hospital.

Government

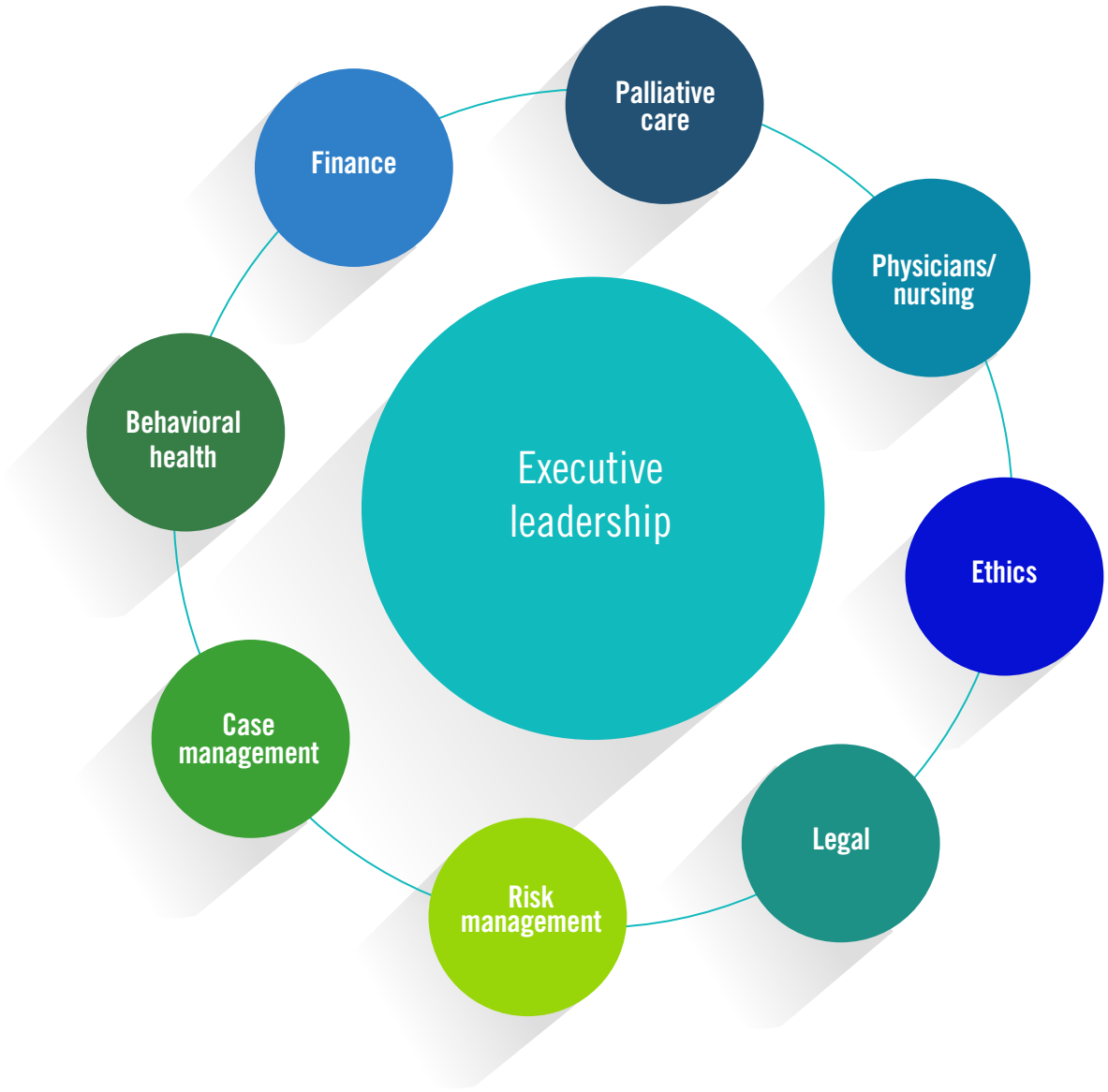
In recent years, the State of New York initiated efforts to address non-medically necessary discharge delays among children with complex case needs and the discharge process for all patients. In 2016, DOH issued a report titled, *The Discharge Planning Process in NYS*, which identified barriers to discharge and offered recommendations for improvement.[66] Many of the barriers mentioned are also the main contributors to complex case discharge delays. New York is also now transforming the state's delivery system for high-needs children served under a number of waiver programs operated by different state agencies.[67] Further, the state recently convened a cross-systems workgroup comprised of all applicable state agencies to address discharge delays among children and youth with complex needs.

Nonprofit organizations

The New York State Conference of Local Mental Hygiene Directors recently issued a report with suggestions for treating individuals with behavioral health disorders and/or developmental and intellectual disabilities.[68] The United Hospital Fund of New York released reports that discuss the transition of complex case patients from hospitals to skilled nursing facilities.[39, 69] The NYS Coalition for Children's Mental Health Services issued a report in 2013 sharing concerns about the pace of regulatory reform and the importance of maintaining capacity in residential treatment facilities.[70] The Center for New York City Affairs at The New School issued a report calling attention to the steep increase in mental health emergencies among young people, and the gaping absence of inpatient care options for children in New York state.[71] In 2019, Capital District Physicians' Health Plan began collaborating with hospitals to deploy a patient care team that coordinates their members' care, answers questions and assists with medication management for discharge planning during their inpatient stay.[72] There are at least 20 organizations statewide whose services are dedicated to helping patients with complex care needs navigate the health and social care systems in New York.

HANYS has discussed the serious problem of complex case discharge delays with senior-level state agency leaders. These conversations have provided the agencies an opportunity to offer insight into their work and thoughts on moving forward together. In October 2019, HANYS began this process by convening providers and stakeholder leaders during a two-day, in-person meeting. This well-attended event reinforced the urgency of the complex case discharge delay problem statewide and helped further define goals to acknowledge and create paths for complex patients to be safely discharged from hospitals. HANYS will continue to work with payers, government agencies, community-based providers and organizations and others essential to preventing patients from falling into the complex case gap in the care continuum.

Hospital complex case discharge delay team example[73]



Next steps

Our goal is to lead efforts to identify systemic and practical solutions to address the disservice to patients who are languishing in inappropriate settings. This white paper is intended to provoke public discourse and collaboration. HANYS suggests the following actions to help patients and hospitals in the short term, while building long-term solutions:

- build and maintain stakeholder dialogue to make New York best in class at solving complex discharge cases;
- establish a senior level, multi-agency response team for cases that should be escalated to "commissioner" level direction, with provider input;
- understand the extent and scope of this issue in New York state by examining the data;
- identify and advocate for changes to regulations or advancement of legislation to remove barriers and create additional care models;
- develop consistent behavioral rules and practices for county agencies, community-based providers and/or other stakeholders;
- build complex case discharge response teams in every hospital and health system;
- educate hospital staff about the full range of resources available; and
- identify clinical and administrative practice and process improvement strategies.

Real examples of common scenarios

45 YEARS OLD
14+ MONTHS INPATIENT

- Arrived with a comorbid psychological condition.
- Was denied eligibility for OPWDD facilities.
- No payment to the hospital after seven days.

59 YEARS OLD
10+ MONTHS INPATIENT

- Arrived as a victim of a hit and run.
- Became ventilator-dependent and semi-comatose.
- Undocumented immigration status.
- Delays due to legal process in obtaining public benefit eligibility status.

71 YEARS OLD
10+ MONTHS INPATIENT

- Arrived after found lying on the street with diminished mental capacity and broken leg.
- Not eligible for shelter placement.
- Family unwilling to assume responsibility for the patient.
- Undocumented immigration status. Delays due to legal process in obtaining public benefit eligibility status.

25 YEARS OLD
7+ MONTHS INPATIENT

- Arrived due to mental health crisis. Co-occurring substance use disorder.
- Cycled between inpatient psychiatric and SUD rehabilitation units.
- Family not comfortable caring for the patient due to a history of multiple overdoses.
- Community residential facilities did not have capacity for wheelchair access.

96 YEARS OLD
2+ MONTHS INPATIENT

- Arrived due to acute decline in Alzheimer's disease.
- Tested positive for infectious disease.
- Denied from subacute rehabilitation centers due to concerns about ability to safely provide care.

16 YEARS OLD

6+ MONTHS INPATIENT

- Arrived when caregivers could not find in-home services or residential placement.
- The patient decompensated dramatically throughout the stay and required three to five beds to minimize disruption to others and two public safety officers at all times.

86 YEARS OLD

6+ MONTHS INPATIENT

- Arrived shortly after a residential facility discovered the patient was a level three sex offender, as it was previously not disclosed.
- No emergency shelter would accept the patient based on criminal history.
- Unreimbursed costs to the hospital were more than $194,000.

15 YEARS OLD

3+ MONTHS EMERGENCY DEPARTMENT

- Arrived when caregivers were unable to secure residential placement after searching for more than one year.
- Estimated costs to the hospital were $195,500, not including legal fees totaling approximately $16,000 and loss due to inappropriate use of a hospital bed. The hospital was reimbursed $74,000.

6 YEARS OLD

3+ MONTHS EMERGENCY DEPARTMENT

- Arrived when family determined they were unable to care for the child.
- Patient was ineligible for available residential treatment services due to age restrictions.

24 YEARS OLD

45+ DAYS INPATIENT

- Arrived with a heart infection and opioid use disorder.
- Required ongoing intravenous treatment.
- Denied from subacute rehabilitation centers due to OUD treatment needs.
- Inability to safely continue intravenous therapy at home due to lack of available services.

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