

Acknowledgements

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NO MORE WAITING Recommendations to begin addressing care delays for New Yorkers with complex needs

Action is needed now to ensure New York's healthcare system is built to serve all New Yorkers, regardless of their care needs. A diverse continuum of statewide healthcare providers agree that New York state must help create and sustain appropriate care options, eliminate payment obstacles and advance ways for children and adults, caregivers and providers to more easily navigate state agency services and benefits.

This report offers potential ways for policymakers to begin addressing this growing and complex issue.

Background

Children and adults with complex care needs and their care providers continue to report long delays in access to essential services. As a result, many seek non-emergency care in hospitals as a last resort and become caught in limbo in emergency departments and inpatient units for weeks, months and even years after they are medically ready for discharge.¹ Complex case discharge delays, also known as bed blocking or boarding, are devastating for patients and their loved ones, exacerbate bed shortages and result in enormous, unnecessary costs.

In 2022, the Healthcare Association of New York State conducted a 90-day data collection pilot, during which 52 hospitals reported that over five hundred people remained in hospitals for a month or more after they were ready for discharge.² Children, older adults and people living with intellectual and/or developmental disabilities or conditions requiring specialty medical care were most profoundly impacted. Delays are most often attributed to difficulty finding safe care options, the inability to pay for care and administrative gridlock.

Diverse organizations representing healthcare providers, county departments of mental health and consumer groups such as The Alliance for Rights and Recovery, Cerebral Palsy Associations of New York State, The Mental Health Association in New York State, New York Alliance for Inclusion and Innovation, Conference of Local Mental Hygiene Directors, Inc. and the NYS Coalition for Children's Behavioral Health have also explored this issue and offered solutions.

While we recognize the state's increased investments and attention to certain areas, broader and more coordinated solutions are urgently needed.

¹Healthcare Association of New York State (April 2021). The complex case discharge delay problem. https://www.hanys.org/communications/publications/complex_case_discharge_delays/docs/complex_case_discharge_delay_problem.pdf

²Healthcare Association of New York State (February 2023). The scope of complex case discharge delays in New York state. https://www.hanys.org/communications/ publications/scope_of_complex_case/docs/complex_case_discharge_delays_survey.pdf

2023 workgroup activity

Our associations representing diverse healthcare providers statewide worked together over the course of several months to develop recommendations to begin the process of achieving more person-centered and equitable healthcare and social care systems for children, adults and families with complex care needs. Recognizing the tremendous complexity of this long-standing problem, we began by working to address the three most significant factors contributing to delays in access to care:

- limited care options;
- challenges in securing payment for essential services; and
- difficulty navigating services overseen by various state agencies.

These workgroups led to the development of the recommendations outlined on the following pages.

Prioritized recommendations

While the reasons for care delays are diverse and complex, we strongly urge the state to increase visibility of the issue and focus on developing solutions. We recommend prioritizing the following actions:

SUSTAINABLE REIMBURSEMENT MODELS: Outdated payment rates that have not kept up with rising costs are putting care across the continuum in jeopardy. State policymakers are urged to update and maintain Medicaid rates that adequately cover the cost of care for residential and community-based services.

CRISIS RESPITE TRANSITION PROGRAMS:

People living with intellectual and/or developmental disabilities, regardless of their enrollment in Office for People with Developmental Disability services, should be able to readily access essential care as they wait for OPWDD eligibility applications to be processed and services to become available. NYC Health + Hospitals and AHRC NYC have piloted such a program with demonstrated success. State policymakers are urged to support the expansion of crisis respite transition programs, including programs for children and adolescents, in regions statewide.

FORMALIZED MULTI-AGENCY PROCESSES:

Healthcare providers continue to report major delays in securing services for children and adults with co-occurring conditions, especially for individuals living with intellectual and/or developmental disabilities. State policymakers are urged to establish formal agency-neutral guidelines to escalate coordination of services for individuals and families whose care needs may require multi-agency involvement, within a set timeframe, with oversight by executive-level staff and consistent with the goals and treatment preferences of those being served.

These recommendations are a starting point to advance a care system that will serve all New Yorkers regardless of the complexity of their needs. More is needed. We urge state policymakers to consider the recommendations on the following pages and take immediate action.

Addressing delays in care access due to **limited care options**

To ensure that all New Yorkers have access to the most integrated setting appropriate to their needs, it is imperative that the state build up integrated and specialty care services, expand non-crisis, transitional care services with immediate access, bolster the workforce, update funding models and have visibility into the care needs of people living with co-occurring conditions.

Integrated and specialty care

Despite innovation by New York healthcare providers³ and new investments, expanding integrated and specialty services remains a major challenge. Healthcare providers are eager to address unmet needs but forced to contend with disparate application and licensure processes and outdated regulations that delay the stand-up of urgently needed services.

We urge the state to simplify requirements and make increased investments in provider-led interventions to ensure the continued viability and responsiveness of New York's healthcare system.

Our integrated and specialty care recommendations include:

Streamline and align multi-agency application and licensure processes.

- Design and implement an interagency plan to provide services to youth and adults with co-occurring conditions.
- Streamline and expand the OMH/OASAS/DOH Integrated Licensure Project.4
- Include OPWDD in the "Integrated Licensure Project" or establish another project that is also inclusive of OPWDD.
- Promulgate regulations to establish a single license for services under the oversight of DOH, OMH, OASAS and OPWDD pursuant to existing statute. (Mental Hygiene Law §31.02 (f), MHL §32.05 (b) (ii), MHL §16.03 (g), PHL §2801.1)
- Align funding cycles and requirements where possible.
- Establish permanent joint funding pools for integrated care initiatives.
- Create a permanent process to evaluate approval of past integrated services and identify areas for improvement.

Remove unnecessary restrictions and increase flexibility.

• Remove licensure restrictions for establishing Integrated Outpatient Services. (14 NYCRR Part 825, 14 NYCRR Part 598, 10 NYCRR Part 404)

³Rockefeller Institute of Government (October 2023) Supporting Individuals with Complex Needs: Care Delivery that Provides the Right Services and Supports in the Right Settings. https://rockinst.org/issue-area/supporting-individuals-with-complex-needs-care-delivery-that-provides-the-right-services-and-supports-in-the-right-settings

^{*}New York State Office of Addiction Services and Supports (December 2023) Integrated Outpatient Services. https://oasas.ny.gov/integrated-outpatient-services

Identify and invest in complex care service models.

- Invest in reimbursed care coordination services for youth and adults who fall or may fall under services overseen by multiple state agencies throughout hospital stays and after discharge.
- Address barriers to collaboration by mental health providers and home care services. (S.5516)
- Advance the Hospital-Home Care-Physician Collaboration model. (PHL §2805-x)
- Consider demonstration projects for skilled nursing facilities providing specialty care.
- Adequately resource residential and community-based care options for youth with complex co-occurring needs, including youth in foster care.
- Invest in the expansion of specialized units in SNFs and/or in specialized training and access to specialty consultation services for SNFs (with or without specialty designations), such as:
 - management of residents who present with challenging behaviors resulting from mental illness, substance use disorders and/or dementia or other neurological conditions; and
 - advanced expertise in managing infectious disease, e.g., Candida auris.
- Expand long-term care options, instead of the hospital, for individuals who are discharged from Department of Corrections and Community Supervision facilities, such as those with sex offender status.
- Invest in the Special Needs Assisted Living Residence voucher program to increase the number of people that can be served by the program and allow vouchers to be used in Enhanced Assisted Living Residence units such that special populations (e.g., those with traumatic brain injuries, bariatric equipment needs and others) may qualify.
- Expand Special Needs Certified Home Health Agencies.
- Expand all neuropsychological services, including specialized services for youth.
- Expand access to dialysis services, including the provision of transportation services.
- Allow nursing homes to establish on-site dialysis dens for residents without obtaining an independent health equity impact assessment of the service.
- Expand supported and supportive housing.
- Consider a pilot wherein individuals who have unstable housing can be discharged to established units at hotels or short-term residences with support until a longer-term placement is established.

Immediate, non-crisis, transitional care

Care needs and the ability for caregivers to provide such care will often unexpectedly change. When a caregiver cannot secure timely and safe care, they are forced to seek such care in a hospital, even when emergency or hospital-level services are not needed. People in need of immediate, non-crisis care are best served in the most integrated setting appropriate to their needs as they wait, for what can be months to years, for their application for services to be processed and services to become available. Our immediate, non-crisis, transitional care recommendations include:

Develop and expand access to immediate, non-crisis, transitional care options.

- Expand the crisis respite transition program model for adults living with intellectual and/or developmental disabilities and mental illness who are and are not yet enrolled in services, following the model set by NYC Health + Hospitals and AHRC NYC's crisis respite transition program pilot.
- Expand emergency respite services and establish temporary support services and/or beds within existing OPWDD programs for children and adults with intellectual and/or developmental disabilities, such as swing beds, for those who are already enrolled in OPWDD and are awaiting longer-term services.
- Implement the New York state cross-system hospital discharge pilot model for youth as proposed by Hillside and Northern Rivers.
- Explore a crisis respite transition program pilot for children, with or without a diagnosed mental illness, who are exhibiting behaviors that require high-intensity support such as increased staffing and modifications to the care environment.
- Expand crisis nursery programs designed to deliver emergency care to children during family crisis, such as the Crisis Nursery of Greater Rochester.

Workforce

Maintaining a robust and stable healthcare workforce is the cornerstone of providing quality care. The availability of care in the community and residential settings is in jeopardy in part due to persistent and historic workforce shortages. Healthcare providers are using every available tool and strategy to recruit and retain their talented, compassionate team members, but challenges remain.⁵ We strongly recommend that the state invest in cross-disciplinary training, allow professionals to work at the top of their credentials, clear obstacles to licensure and certification and expand telehealth.

Our workforce recommendations include:

Invest in cross-disciplinary training and educational opportunities.

- Invest in programs like Project Training and Education of the Advancement of Children's Health (TEACH) and Extension for Community Healthcare Outcomes (ECHO) that focus on populations with complex care needs in residential and community-based care settings such as neonatal abstinence syndromes presenting as intellectual and/or developmental disabilities and mental health for individuals living with serious medical conditions.
- Share information regarding ways educational institutions may incorporate related competencies such as those included in the Golisano Institute for Developmental Disability Nursing.
- Promote the integration of applied behavior analysts into hospitals and other settings as appropriate.

⁵Center for Health Workforce Studies (April 2023) The Health Care Workforce in New York State: Trends in the Supply of and Demand for Health Care Workers. https://www. chwsny.org/wp-content/uploads/2023/05/Health-Care-Workforce-NYS-Trends-2023-Final.pdf

Allow professionals to work at the top of their credentials.

- Permit nurse practitioners and physician assistants to make the determination regarding use of restraint and seclusion. (14 NYCRR §526.4)
- Permit psychiatric nurse practitioners to admit mental health patients to licensed mental health facilities on a voluntary and involuntary basis. (A.6934)
- Allow psychology trainees to provide Medicaid-reimbursable services under the supervision of a licensed psychologist in Article 28 settings.
- Establish the qualified mental health associate paraprofessional role.
- Authorize certified medication aides to administer routine and prefilled medications in residential healthcare facilities. (A.08299)

Expedite licensure and certification.

- Authorize New York to join the Nurse Licensure and Interstate Medical Licensure compacts (A.6421 and A.4860/S.2216) and establish compacts for other professions, e.g., licensed clinical social workers.
- Permit qualified high-need, out-of-state healthcare professionals to practice in New York under a temporary practice permit while awaiting New York state licensure. (A.6697 as introduced)

Promote licensure and certification incentives.

- Establish career pathways for high-need direct care professionals, such as opportunities for education and training and apprenticeship programs.
- Maintain loan forgiveness programs for high-demand professions and specialties, e.g., OMH Community Mental Health Loan Repayment Program, Doctors Across New York and Nurses Across New York.
- Fund the expansion of psychiatry residency programs and geriatrics training for physicians, nurse practitioners and social workers, with rotations across inpatient, outpatient, home and community-based providers.
- Partner with high schools and higher education programs to encourage entry into geriatric medicine, such as the New Jewish Home's Skill Spring program.

Expand telehealth.

- Allow and reimburse for telehealth services in all settings as appropriate, e.g., SNFs, home care, adult care facilities and OPWDD programs. For example:
 - update DOH guidance (DACF 23-27, DHCBS 23-04, DNH 23-19).⁶
- Allow clinicians licensed outside of New York state to provide care through telehealth to New York state residents. (A.7447-A/S.7432-A)

⁶New York State Department of Health (October 2023) Telehealth in Adult Day Health Care, Home Health Care, Hospice, and Adult Care Facilities. https://www.health.ny.gov/ facilities/adult_care/dear_administrator_letters/docs/dal_23-27.pdf

Reimbursement

Medicaid and Medicare have long underpaid providers for the cost of care. For example, Medicaid payments averaged 76 cents on the costs of care in 2019 for skilled nursing facilities, and rates have only fallen farther beyond costs in the years since.⁷ Other care providers are experiencing similar shortfalls. The current payment system has not adapted to, nor have the resources of providers aligned with, the evolving needs of the population. Adequate reimbursement from all payers is essential to sustaining existing services and investing in the updated facilities and service models we need to serve the increased complexity of New Yorkers.

Our reimbursement recommendations include:

Evaluate and update reimbursement methodology.

- Provide a multi-year commitment to close the Medicaid payment gap for nursing homes.
- Establish a complex care program that provides incentive payments necessary to care for children and adults in need of specialty care. For example, Monroe County used American Rescue Plan funds to establish such a program for SNFs. Enhanced reimbursement is necessary to provide:
 - specialty training and consultations, e.g., pediatric subspecialties, intellectual and/or developmental disabilities, dementia, psychiatry and infection control;
 - environmental modifications necessary to provide care to individuals with a broader range of mobility and behavior support needs, such as individuals living with mental illness who require adaptive equipment;
 - additional staff for higher intensity care such as individuals in need of 1:1 special observation to maintain safety; and
 - accommodations for individuals with a history of criminal justice involvement such as those with sex offender status.
- Reinstate the full Medicaid payment for SNF residents who are temporarily hospitalized (for up to 14 days). (Public Health Law 2808 Section 25(a))
- Allow hours worked by RNs and LPNs in SNFs to count toward aide hours for purposes of the nursing home minimum staffing requirements, in order to support care for medically complex residents who may require more nurse hours.
- Strengthen the expertise necessary to account for long-term savings and systemic benefits by better connecting the program and budget sides of regulatory agencies.

Enforce behavioral health parity.

- Ensure commercial insurance reimbursement for mental health and substance use outpatient providers are at least on par with the Medicaid ambulatory patient group rates. (A.8807/S.8307, Part AA)
- Increase oversight of managed care plans to ensure they are paying government-mandated rates and not inappropriately denying behavioral health claims. (A.8807/S.8307, Part H)

⁷Medicaid and CHIP Payment and Access Commission (January 2023) Estimates of Medicaid Nursing Facility Payments Relative to Costs. p. 15. https://www.macpac.gov/ wp-content/uploads/2023/01/Estimates-of-Medicaid-Nursing-Facility-Payments-Relative-to-Costs-1-6-23.pdf

Visibility

To ensure New Yorkers of all ages and health conditions have adequate access to services, it is important to have a holistic understanding of their care needs. Despite widespread recognition that a large proportion of our community is living with multiple conditions, public health surveillance and interventions are overwhelm-ingly based on individual conditions. We must invest in data collection and public health models that are person-centered and allow for more informed healthcare delivery planning.

Our recommendations to increase visibility include:

Increase visibility and acknowledgement of New Yorkers with complex care needs.

- Ensure the prevalence and care needs of children and adults with complex conditions are visible and included in every applicable state agency's assessment and strategic plan.
- Gain a shared understanding of service capacity needs for individuals with co-occurring conditions or those in need of specialty services by examining readily available data, e.g., Statewide Planning and Research Cooperative System and Medicaid data.
- Explore waitlist size, wait times for certain services and utilization rates to better understand the demand for care.
- Conduct surveys and/or interviews with service providers and consumers to gain more insight into perceived capacity and local variation.

Addressing delays in access due to **securing payment for care**

Despite payment reform efforts, New Yorkers continue to face unnecessarily convoluted processes to secure payment for essential services. Rather than helping to facilitate timely care, insurers cease paying for non-acute care or reimburse at an insufficient alternate level of care rate in hospitals. They also present patients and providers with a dizzying maze of administrative obstacles. Streamlining prior authorization and adopting patient-centered payment models are important steps to ensure New Yorkers receive the care they need when they need it.

Insurance eligibility and transitions

While New York has taken many steps to increase access to insurance, there are many who still do not qualify for coverage that meets their healthcare needs. As a result, it is not uncommon for people to live in hospitals for months to years when they are not eligible for public insurance and require community-based or residential care.

Our insurance eligibility and transitions recommendations include:

Expand Medicaid and the basic health program or establish a fund for individuals who require long-term care but are ineligible for Medicaid.

• Secure payment for appropriate care of people who are undocumented non-citizens or non-New York state residents. (A.3020-A/S.2237-A)

Establish a fund to cover the cost of essential care during insurance transition waiting periods.

• Allow children and adults in need of hospice services to receive immediate hospice care as they wait for insurance application benefits to be processed, rather than wait in the hospital.

Streamline Medicaid eligibility determinations.

- Develop a mechanism for all relevant parties to track Medicaid applications electronically and regularly identify and respond to the causes of extended delays, rather than relying on postal mail correspondence.
- Make insurance transitions effective immediately or retroactively, rather than on the first of the month.
- Identify ways to establish consistent insurance coverage for children, adults and families who may easily fall in and out of eligibility criteria or transition from one program to another.
- Streamline insurance transitions such as from commercial insurance to Medicaid and from Health and Recovery Plans to mainstream Medicaid.

- Expedite interstate transfer of Medicaid coverage for people who are unable to undergo a necessary care transition due to lack of payment for care, and as a result, are forced to seek care in hospitals.
- Establish pre-arranged agreements or regularly review Medicaid eligibility criteria for other states to process Medicaid applications more quickly, instead of waiting up to 90 days.

Prior authorization

While prior authorization is aimed at cost-control, it can directly result in harm to children, adults and their caregivers while artificially driving up healthcare costs. Clinicians, who are in shortage, are forced to grapple with persistent administrative obstacles to secure essential care for their patients, instead of providing desperately needed direct care services. According to a 2022 American Medical Association survey of physicians:

- 94% of responding physicians reported that the prior authorization process delayed patient access to necessary care.
- 33% reported that prior authorization has led to a serious adverse event for a patient in their care.⁸

New York state must stop overly burdensome prior authorization policies and practices from standing in the way of access to care and unnecessarily inflating healthcare costs.

Our prior authorization recommendations include:

Eliminate unnecessary prior authorization requirements.

• Exempt healthcare professionals from preauthorization requirements if health plans have approved not less than 90% of their requests in the preceding six-month evaluation period.

Reduce or eliminate prior authorization delays.

- Support the elimination of the Medicare SNF three-day hospital stay requirement as a condition of coverage of SNF care. (Section 1861(i) of the Social Security Act and 42 CFR 409.30)
- Reduce commercial plans' and Medicaid managed care prior authorization response times.
- Prohibit payers from requiring unnecessary documentation as a delay tactic.
- Require payers to maintain and publish data on denials and timelines for preauthorization requests and decisions.
- Invest in automated information exchange platforms between providers and payers, including the removal of postal mail communication.

⁸American Medical Association (March 2023) 2022 AMA prior authorization physician survey. https://www.ama-assn.org/system/files/prior-authorization-survey.pdf

Default to approval of coverage when health plans are non-responsive.

• Treat the failure of a plan to make a determination within the established timeframes as an approval of services, rather than a denial.

Enforce and strengthen preauthorization requirements.

• Put in place penalties when payers fail to respond to authorization requests in one business day for inpatient rehabilitation services following an inpatient hospital admission.

Network adequacy

Network adequacy is a major, longstanding obstacle to care, especially for individuals seeking mental health services. Public health emergency-era flexibilities in New York state temporarily removed delays in access to care due to network coverage limitations. Stricter enforcement of network adequacy standards and reinstatement of pandemic flexibilities, as appropriate, will help eliminate care delays.

Our network adequacy recommendations include:

Reform network adequacy standards and invest in the enforcement of such standards, including ongoing surveillance.

- Reinstate network coverage flexibilities that were demonstrated to be effective during the COVID-19 pandemic (see DFS CL 8, 2020).⁹
- Require DOH and DFS to conduct a quarterly analysis of the Provider Network Data Set data, aggregated by health plan and service type, and make the analysis publicly available.
- For mainstream Medicaid managed care plans that fail to meet the Network Adequacy standards per the Model Contract, automatically trigger the imposition of sanctions, including fines of no less than \$10,000 per instance of non-compliance (see MMC Model Contract, Section 27 for discussion of intermediate sanctions).

⁹New York State Department of Financial Services (March 2020). Insurance Circular Letter No.8: Coronavirus, Utilization Review, and Emergency Admission Notification Requirements. https://www.dfs.ny.gov/industry_guidance/circular_letters/cl2020_08

Addressing delays in access due to lack of interagency service coordination

A lack of care options and inability to cover the cost are the primary contributors to delays in access to care for youth and adults with complex care needs. However, substantial delays in state agency processes to determine eligibility and secure services and benefits also contribute significantly.

Despite robust efforts to advance interagency coordination, more synergy across agencies is needed at the state and local levels. Individuals and families with co-occurring conditions must navigate separate and distinct processes from multiple oversight agencies to access services, resulting in unnecessary care delays and fragmentation. For example, hospitals may work with more than 20 government entities to secure safe and appropriate post-discharge care for a single patient.

Our interagency service coordination recommendations include:

Formalize agency-neutral guidelines to escalate cases with potential multi-agency involvement.

• Establish multi-agency guidelines that include the development of disposition plans within a set time frame, with oversight by executive-level staff and consistent with the goals and treatment preferences of those being served.

Institute consistent rules and practices.

- Create joint agency guidelines for the process of determining service eligibility and responsibility when it is unclear which agency will be responsible for providing services.
- Develop core competencies and mechanisms for processing applications and identifying appropriate placement.

Establish a single point of entry for all services and benefits.

- Develop a core application for all agency services and benefits, with attachments that meet the needs of each agency.
- Streamline consent.
- Institute a single point of contact or hub for care providers to direct questions about services across agencies, with direction to counties as appropriate, e.g., local government units.
- Develop a consumer and agency-facing electronic-based application system to gain insight into the status of applications and more quickly provide necessary documentation such as that used for the New York State of Health.

Establish an interagency initiative to assess and develop solutions to improve the eligibility and referral process.

• Participants in the interagency initiative should routinely conduct case evaluations and review available data, identify relevant statutes, regulations, processes and funding mechanisms that may be adjusted to address unmet needs. The initiative should also include service providers, consumers and caregivers.

Leverage data to create visibility into the eligibility and referral process.

- Conduct periodic monitoring of the time it takes to move through the eligibility process and reasons for delays to better understand how to eliminate unnecessary administrative delays in accessing care and more quickly determine resource needs.
- Establish an acceptable eligibility and referral processing time for each level of need as a benchmark and evaluate data to identify systemic challenges more quickly.
- Create a joint agency dashboard to facilitate information sharing and problem solving.

Increase investment in and support for existing interagency taskforce groups and initiatives.

- Provide the Council for Children and Families with advanced clinical expertise and data and evaluation professionals to advance their ability to identify challenges and facilitate problem-solving between agencies.
- Consider the development of an agency like CCF for adults.

Cultivate a shared understanding of and expectations for the eligibility and referral process.

• Create opportunities to foster joint problem solving and routinely update and provide healthcare providers, caregivers and consumers with guides, trainings and tools on service access and application processing in coordination with applicable state agencies.

Next steps

The current system does a disservice to our communities and people who "live" in hospitals or are otherwise unable to access the care they need. There may not always be a perfect care option for children and adults with complex care needs — but there is a shared responsibility to acknowledge and find the best solutions to this issue.

These recommendations are a starting point to build a care system that serves all New Yorkers, regardless of the complexity of their care needs. Our associations will continue to work toward solutions and look forward to continuing to partner with policymakers, additional healthcare providers, consumers and all interested parties.

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