Senator Samra Brouk, 55th S.D.
Assemblymember Sarah Clark, 136th A.D.

Call to Action!

Solutions for Youth with Unmet Complex Needs

WELCOME!

Call to Action!

Solutions for Youth with Unmet Complex Needs

RIGHT NOW,

in Monroe County and across the region,

youth with complex intellectual and developmental disabilities (I/DD), behavioral health, and/or mental health needs are being repeatedly hospitalized for extended periods of time, languishing on waitlists, sitting in detention, and being driven into the foster care system due to the dearth of meaningful and available community-based services and supports and lack of residential options for those who need it. **The current continuum of care is not meeting the needs of youth and families.**

The lack of access

to the right care at the right time is causing children to have extended stays of **up to 243 days** in a hospital setting. **Families can wait months to years without adequate services in place.**

Capable, loving families are often in the position of choosing between taking unsafe children home or risking a CPS report if they refuse. **No parent should be put in the position of placing their child in foster care to access the level of care their child needs.**

The reality is that foster care, as a system of last resort, is ill-equipped to adequately serve youth with complex care and I/DD needs.

Source: 8.26.2024 "Call to Action" Letter - Monroe County Executive Office

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Solutions for Youth with Unmet Complex Needs

ACCESS TO CARE FOR CHILDREN AND YOUTH

IN THE PAST YEAR, 2/3RDS OF FOSTER CARE YOUTH

presenting with complex, higher level of needs and determined to need residential/congregate care, were placed in out of county placements - **as far away as Albany** (*3 hrs drive from Monroe County*).

Monroe County DHS

IN 2023

249 children

youth **were sent to out-of-state residential programs** by a local department of social service (15) or by a Committee on Special Education (234).

NYSCCF 2023 Annual Report

Nearly one in seven children aged 2 to 8 years in the United States has a mental, behavioral, or developmental disorder. Among children and adolescents aged 9 to 17 years, **as many as one in five** may have a diagnosable psychiatric disorder. **Yet not a single state in the country has an adequate supply of child psychiatrists**, and 43 states are considered to have a severe shortage.

Improving access to children's mental healthcare infographic; CDC

FAMILIES WAIT MONTHS...

to YEARS

to be offered eligible services - **families burn out before supports are offered** and accessing medical care/ER hospitalization becomes seen as the only viable support.

Monroe County DHS

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Solutions for Youth with Unmet Complex Needs

64% of Monroe County youth in the child welfare system eligible for OPWDD services were not receiving them, while the same was true for 57% of those youth eligible for OMH services.

64%

Between 2021 and 2023, visits to the hospital by child welfare youth rose 61%.

Source: Cross-Sector Convening document

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Solutions for Youth with Unmet Complex Needs

REAL FAMILIES RIGHT NOW

Monroe County DHS

Youth Circumstance #1:

- Youth is deaf/hard of hearing, has an indicated IQ of 54, a diagnosis of Fetal Alcohol Syndrome, and is the victim of sexual abuse by a caregiver.
- Youth displays physical aggression and displays of problematic sexualized behaviors.
- Has currently been in-patient at a Comprehensive Psychiatric Emergency Program for over 8 weeks.
- Bio-Father is incarcerated in Federal prison.
- Bio-Mom is currently living with the adult male that perpetrated the alleged sexual abuse to the youth = Mom cannot be deemed caregiver.
- No placements available or accepting referral.

Youth Circumstance #2:

- Youth with I/DD diagnosis – Autism, IQ <70, Physical aggression and intensive behavior support needs.
- Parents extremely invested and willing to try to support youth. Worked tirelessly to support their family member.
- Youth could no longer be safely managed in the family home – no other system had available options.
- Youth was admitted in-patient and spent 4 months boarding at local hospital.
- Family HAD to place youth in to foster care, to get needs met that could have been met through other systems.

The very real circumstances that families are facing underscores the URGENT need for collective and coordinated response and support.

Source: Monroe County DHS

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Solutions for Youth with Unmet Complex Needs

HOW LONG IS TOO LONG?

Information from University of Rochester Medicine

Length of Stay

243

Days

13 year old male

- Presented to Strong Memorial due to an increase in aggressive behaviors.
- Discharge to residential scool placement at Easter Seals Kessler Center confirmed for January 2022, after extensive advocacy with the home school district.
- No in-home services through OPWDD could be identified during lengthy stay due to lack of staffing in a community setting.
- Multiple agency involvement has been needed.

10 year old female

- From Erie County and presented to Strong Memorial a day after being discharged from ECMC.
- Presented with previous aggressive behavior and a history of autism, developmental delay, and intellectual disability.
- Awaing residential school program or increase in in-home and community services/supports.
- Multiple agency involvement has been needed.

Length of Stay

152

Days

Length of Stay

251

Days

17 year old male

- Discharge is being planned for this week or next after an extensive stay.
- Presented at Strong with aggressive behavior.
- No in-home services through OPWDD could be identified during lengthy stay due to lack of bilingual staff in a community setting.
- He was declined from residential school programs and remains on home/hospital tutoring for the time being due to lack of in-district placement.

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Solutions for Youth with Unmet Complex Needs

“Why do willing and caring parents have to reach the point of seeking foster care to get their child’s needs met?”

~ Monroe County DHS

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Solutions for Youth with Unmet Complex Needs

SCOPE OF THE CHALLENGE

Growing 40% Faster

Children under 21 constitute approximately one-third of the people served by OPWDD, and this age segment is growing nearly 40% faster than our service population overall.

OPWDD 2023-2027 Strategic Plan

An estimated 1-3% of children and youth have an ID/IDD, with as many as 40% of those children experiencing a co-occurring mental health disorder. However, only approximately 1 in 10 children with a co-occurring I/DD and mental health disorder receive specialized mental health services.

A Safe Place to Be: Crisis Stabilization Services and Other Supports for Children and Youth; SAMHSA, September 2022

Only **1 in 10** children with I/DD and mental health needs receive specialized services.

38-49% of children with I/DD also have psychiatric symptoms.

An international review of 19 studies, including a collective sample of 6151 children and adolescents from across the globe, found that 38% - 49% of children with I/DD also have psychiatric symptoms. Overall, these estimates are much higher than the prevalence (14%) in typically developing children and adolescents.

Source: Buckley, N., et al., Australian & New Zealand Journal of Psychiatry. May 2020

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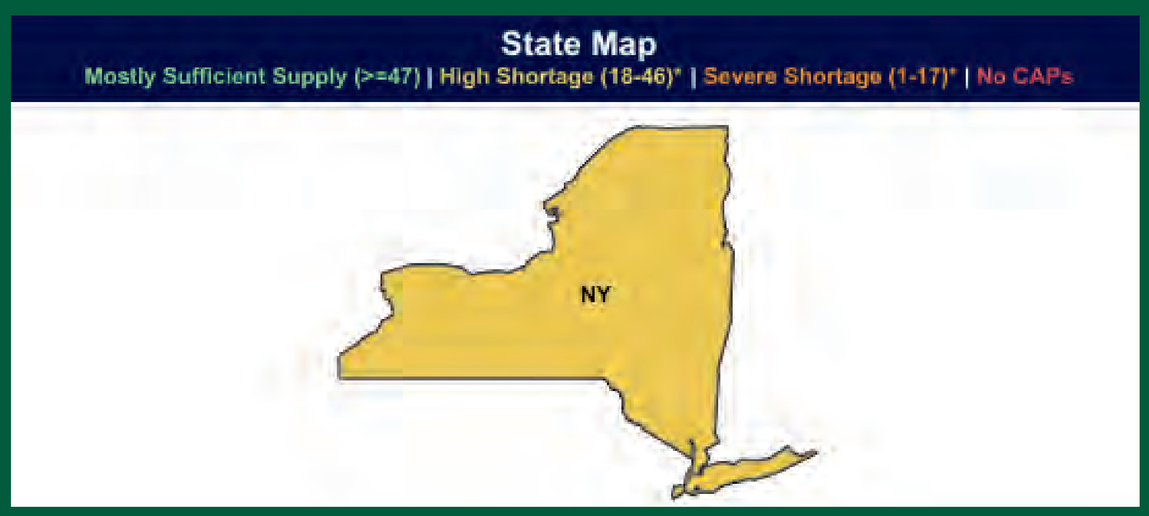
Solutions for Youth with Unmet Complex Needs

SHORTAGE OF PRACTICING CHILD AND ADOLESCENT PSYCHIATRISTS (CAPs) IN THE STATE OF NEW YORK



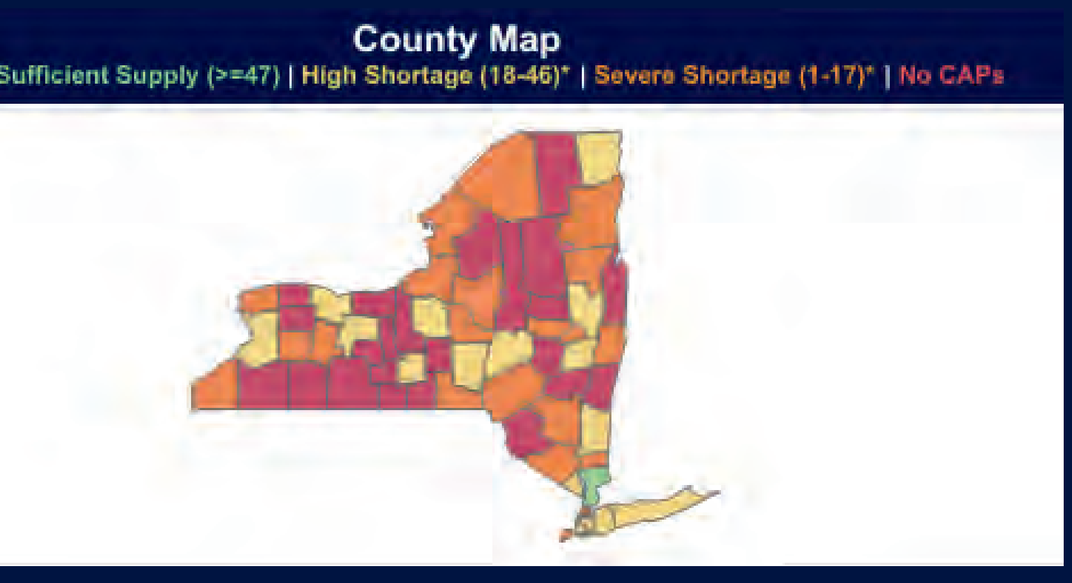
IN THE STATE OF NEW YORK

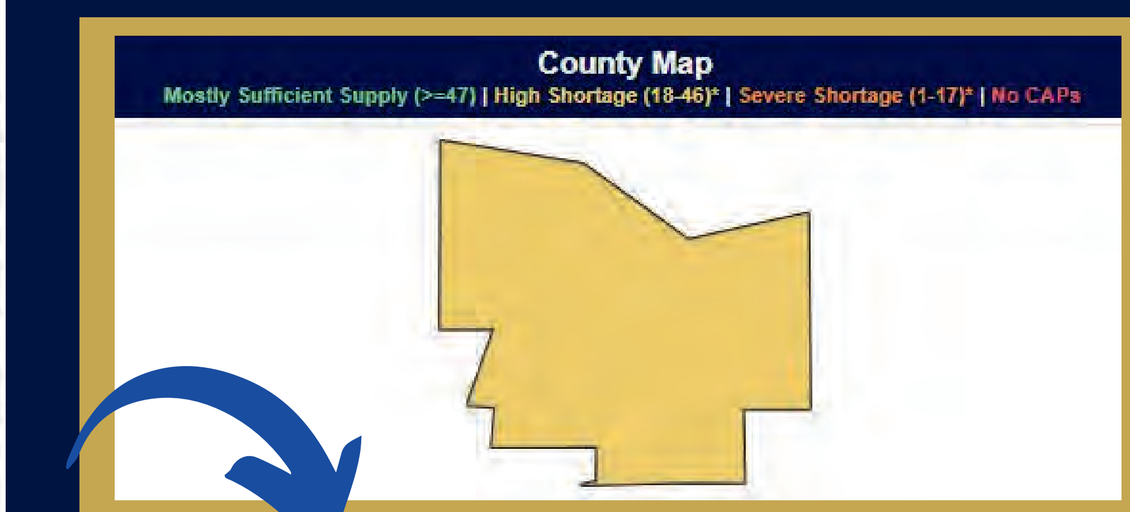
- 4,128,443 Children <18
- 1,257 Total CAPs
- 30 CAPs/100k Children
- 37% No CAP Counties

CAPs BY EACH NEW YORK COUNTY

New York County	CAPs	# of CAPs/100k Children	Pop < 18
Albany	13	23	57,079
Allegany	0	0	9,265
Bronx	52	15	355,908
Broome	4	11	37,897
Cattaraugus	0	0	16,876
Cayuga	0	0	14,810
Chautauqua	1	4	25,842
Chemung	0	0	17,589
Chenango	2	21	9,672
Clinton	4	28	14,325
Columbia	0	0	10,101
Delaware	1	14	7,235
Dutchess	12	22	55,027
Erie	41	21	191,335
Essex	1	17	5,915
Franklin	0	0	9,647
Fulton	0	0	10,634
Genesee	0	0	11,822
Greene	0	0	7,778
Hamilton	0	0	665
Herkimer	0	0	12,343
Jefferson	1	4	27,944
Kings	127	21	604,364
Lewis	0	0	6,112
Livingston	1	9	11,048
Madison	1	8	12,723
Monroe	52	34	154,969
Montgomery	1	9	11,377
Nassau	131	44	297,719
Niagara	6	14	42,089

New York County	CAPs	# of CAPs/100k Children	Pop < 18
Oneida	2	4	49,228
Onondaga	34	34	99,353
Ontario	4	18	21,901
Orange	12	12	101,997
Orleans	0	0	7,690
Oswego	2	8	24,452
Putnam	1	5	19,058
Queens	112	24	469,856
Rensselaer	1	3	30,603
Richmond	11	10	106,747
Rockland	20	21	97,168
Saratoga	15	33	45,784
Schenectady	1	3	34,078
Schoharie	0	0	5,219
Schuyler	0	0	3,365
Seneca	0	0	6,743
St. Lawrence	2	9	21,696
Steuben	0	0	20,046
Suffolk	78	25	316,671
Sullivan	0	0	16,516
Tioga	0	0	9,844
Tompkins	4	27	14,870
Ulster	4	13	31,525
Warren	2	17	11,647
Washington	0	0	11,289
Wayne	0	0	19,291
Westchester	150	70	214,632
Wyoming	1	13	7,977
Yates	0	0	5,437





IN MONROE COUNTY

- 154,969 Children <18
- 52 Total CAPs
- 34 CAPs/100k Children

Source: American Academy of Child & Adolescent Psychiatry State Workforce Maps

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Solutions for Youth with Unmet Complex Needs

INTERNATIONAL EXPERTS AGREE

Adequately supporting youth with multiple complex needs (MCN) requires all professionals to work collaboratively and join resources to achieve common goals. Several experts point out that limited communication and coordination of services across sectors is not sufficient to ensure that the needs of youth with MCN are adequately addressed, arguing the critical importance of integrated care. They argue that it is critical to fully integrate services provided across systems such as mental health, behavioral health, juvenile justice, and child welfare as a means of improving measurable outcomes for the most vulnerable children. The idea that more complex child and family needs require stepping up on the collaboration spectrum is widely endorsed in the broader literature on interagency collaboration.

Source: Towards a definition of multiple and complex needs in children and youth: Delphi study in Flanders and international survey.
Van den Steene H, et al. May 30, 2019

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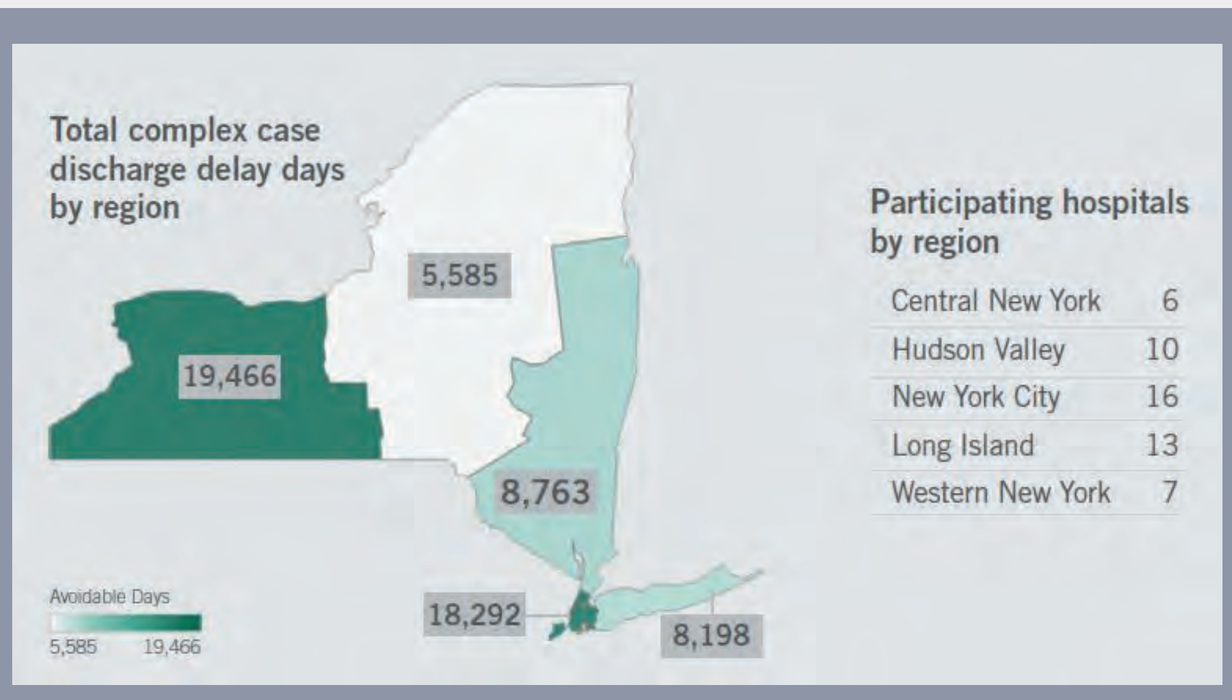
Solutions for Youth with Unmet Complex Needs

RIGHT CARE, RIGHT TIME: A FRAMEWORK FOR CHANGE

Hospitals are sentinels for the health needs in our communities. When all other care options are exhausted and preventative care is not accessible, patients arrive at the hospital. When safe post-discharge care is not available or delayed, patients have no choice but to wait in the hospital.

HANYS developed the following framework to help focus efforts to ensure patients no longer languish in hospitals for months to years after they are ready for discharge.



Intervene Early

Establish a multi-agency escalation process for patients who are at high risk of discharge delay; create a timeline for development of discharge plans in coordination with relevant agencies; eliminate payment barriers for post-discharge care; and prioritize patients in the hospital for legal and administrative processes.

Increase Visibility

Create benchmarks and use state and agency data on the time between when services are sought to when they are received to more quickly identify and respond to changes in care needs.

Prevent unnessary hospital visits and discharge delays due to limited care options

Expand and expedite access to more appropriate and therapeutic care settings so that individuals who are in need of services, but not hospital-level care, are not forced to go to the hospital or stay for months to years as a last resort; educate the public, schools, law enforcement and others about care in the community and other supportive resources.

Respond to patient needs during unavoidable extended discharge delays

Provide support to hospitals to ensure they can meet patient needs, e.g., education and emotional well-being; ensure hospitals are reimbursed for services they provide.

Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

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Solutions for Youth with Unmet Complex Needs

COMPLEX NEEDS:

In 2019, a cross-sector, international panel of experts agreed that children and adolescents with multiple and complex needs have profound challenges in several life domains as well as psychiatric needs AND the capacity (expertise and resources) of existing services do not adequately meet the needs of these youths and their families. Cross-sector, integrated and assertive care delivery is necessary for safeguarding the wellbeing, development and societal integration of young people with multiple and complex needs.

Avoidable Discharge Delays: Children Waiting in Hospitals Deserve More Attention
Emma J. B. Gerstenzang, MD, et al. Hospital Pediatrics. Feb 2023

HOSPITAL DISCHARGE DELAY:

The American Case Management Association defines an “avoidable delay” in the hospital as “any barrier to facilitating effective, efficient, timely and safe care…that causes an extension in the patient’s length of stay…of four hours or more.

A literature review and clinical experiences suggest there are several groups of patients at higher risk. These populations include children with (1) behavioral health needs, (2) complex medical conditions, and (3) child welfare system involvement.

Source: Towards a definition of multiple and complex needs in children and youth: Delphi study in Flanders and international survey.
Van den Steene H, et al. May 30, 2019

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Solutions for Youth with Unmet Complex Needs

Hospitals across the country

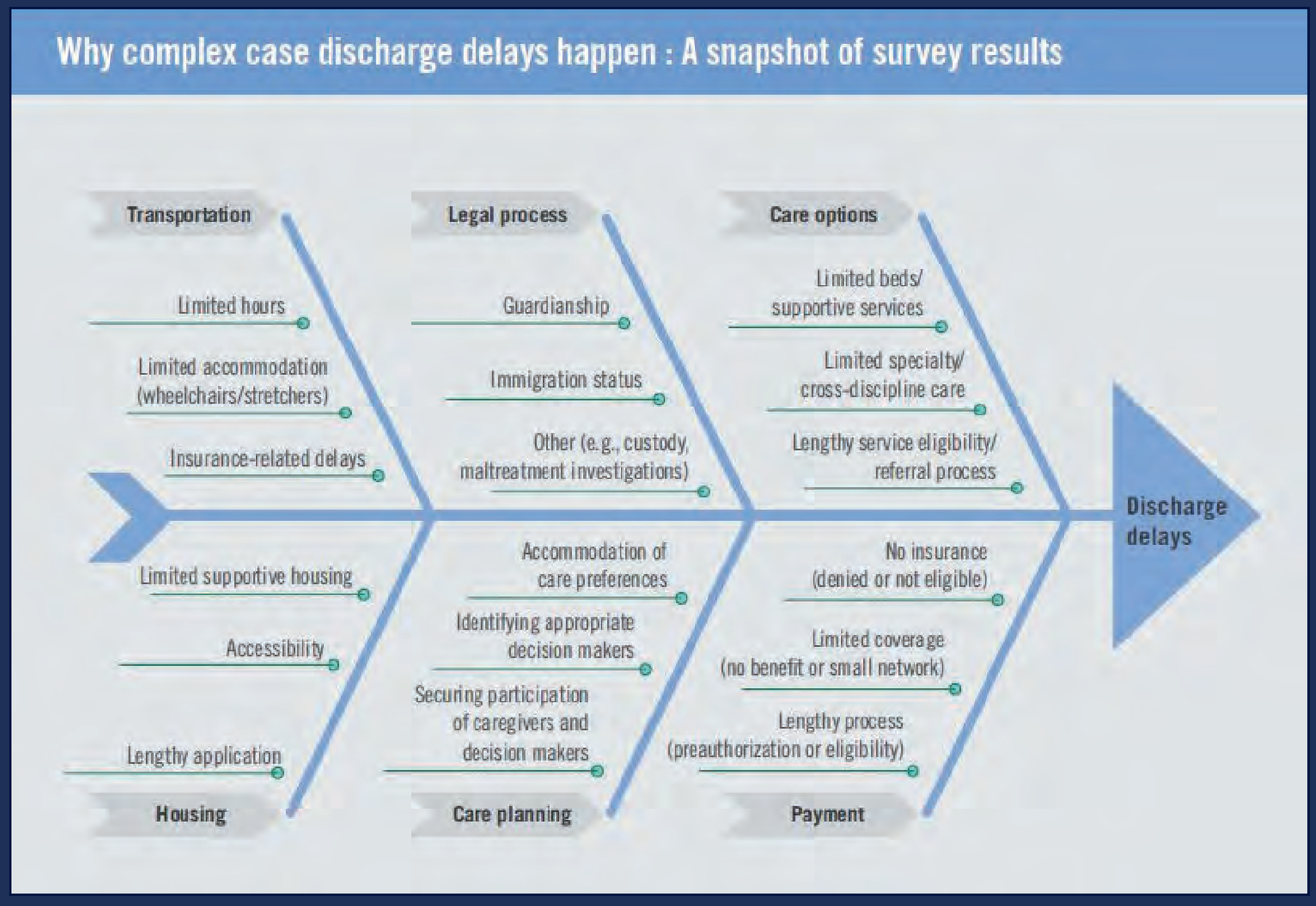
have reported an alarming rise in patients who become caught in limbo in emergency departments and inpatient units for weeks, months and even years after they are medically ready for discharge.

Data Collections Results:

	MOST FREQUENT	LONGEST DELAYS
WHO IS IMPACTED?	• Older than age 65 • Medical complexity, e.g., dialysis	• Younger than age 18 • Individuals with intellectual/developmental disabilities and/or mental illness
WHAT IS CAUSING THE DELAYS?	• Lack of care options • Lack of payment for discharge setting	• Guardianship • Agency process (eligibility/referral)

KEY FINDINGS:

- 1,115 patients;
- 60,000 delay days;
- $169 million in estimated costs
- average ED discharge delay of close to 2 weeks
- average inpatient discharge delay of two months



The Healthcare Association of NYS (HANYS) 2021 white paper, *The complex case discharge delay problem,* outlined the unintended consequences of a system that does not "see" complex case patients, based on the experiences of hospitals and patients. Their 3-month data collection pilot with hospitals statewide helps us learn more about the scope of complex case discharge delays in New York.

Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

The data collection results demonstrated tremendous care gaps for individuals with complex care needs. The healthcare system must be designed for individuals with co-occurring care needs as the expectation, not the exception.
The need for change is urgent.

Call to Action!

Solutions for Youth with Unmet Complex Needs

YOUNG PEOPLE WITH COMPLEX CIRCUMSTANCES NEED OPTIONS FOR WHAT'S NEXT (Post-Inpatient)

WHO IS IMPACTED?

Inpatient:

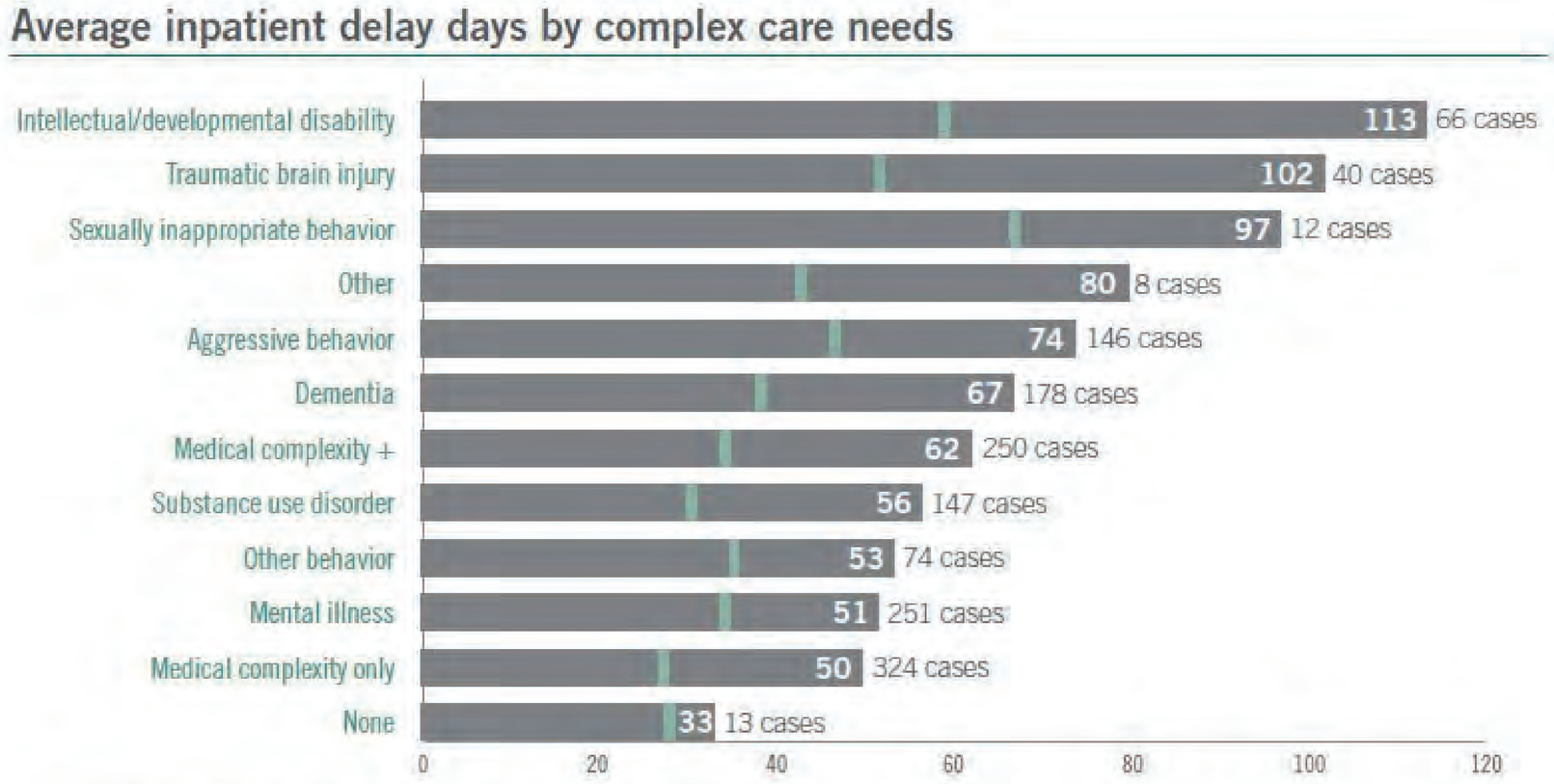
Fifty hospitals reported 992 patients with discharge delays of more than two weeks in their inpatient units between April 1 and June 30, 2022. Over half experienced a discharge delay of over one month. Almost half of these patients were 65 years of age or older. **However, young adults and children experienced the longest average delays at about three months compared with two months for individuals who are older than 65 years of age.**

Inpatient discharge delays by region and statewide

Regions	# Hospitals	# Patients	Avg. delay days	Total delay days
Central New York	5	124	41	5,100
Hudson Valley	10	134	65	8,641
Long Island	13	141	58	8,190
New York City	16	306	59	18,076
Western New York	6	287	58	18,703
Statewide	50	992	59	58,710

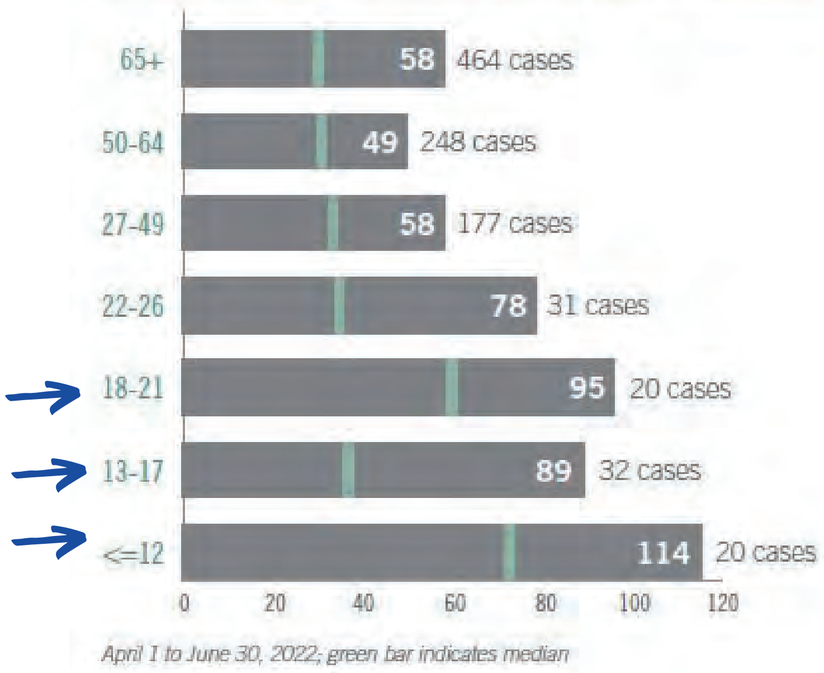
Inpatient cases, April 1 to June 30, 2022

Average inpatient delay days by complex care needs



"Select all that apply" question; April 1 to June 30, 2022; green bar indicates median

Average inpatient delay days by age



April 1 to June 30, 2022; green bar indicates median

People most commonly delayed in inpatient units were those living with a medical complexity and/or mental illness and those who were living at home with caregiver support prior to hospitalization.

Individuals with intellectual and developmental disabilities and/or who were transferred from another acute care hospital or had unstable housing/were unhoused had the longest average delays.

Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

Call to Action!

Solutions for Youth with Unmet Complex Needs

YOUNG PEOPLE WITH COMPLEX CIRCUMSTANCES NEED OPTIONS FOR WHAT'S NEXT (Post-ED)

WHO IS IMPACTED?

Emergency Department:

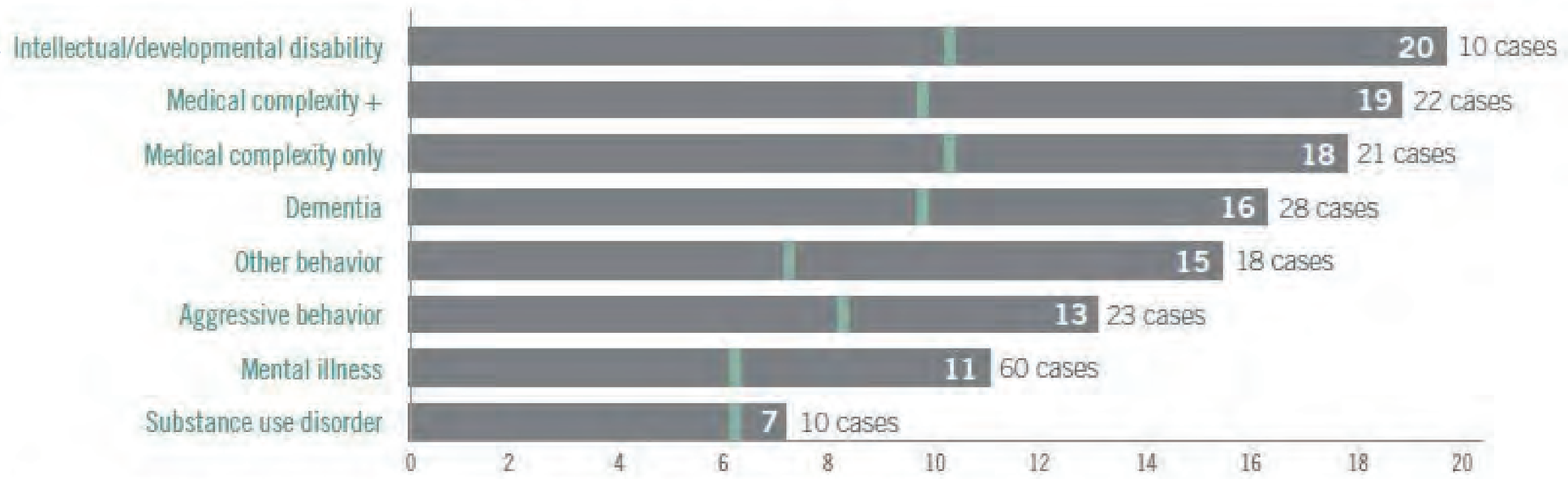
Twelve hospitals reported 123 patients with discharge delays of more than four days in their ED between April 1 and June 30, 2022. Adults age 65 and older, **patients with mental illness and/or those who previously resided at home with caregiver support most often experienced delays. Patients with intellectual or developmental disabilities** and those who previously lived in an assisted living facility experienced the longest average delays.

ED delays by region and statewide

Regions	# Hospitals	# Patients	Avg. delay days	Total delay days
Central New York	4	46	11	487
Hudson Valley	3	11	11	122
Long Island + NYC	2	24	9	224
Western New York	3	42	18	763
Statewide	12	123	13	1.598

April 1 to June 30, 2022

Average ED delay days by complex care needs



"Select all that apply" question; removed categories with <5 patients; April 1 to June 30, 2022; green bar indicates median

Average ED delay days by age

April 1 to June 30, 2022; green bar indicates median

Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

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Solutions for Youth with Unmet Complex Needs

WHAT IS THE FINANCIAL COST OF DELAYED HOSPITAL DISCHARGE?

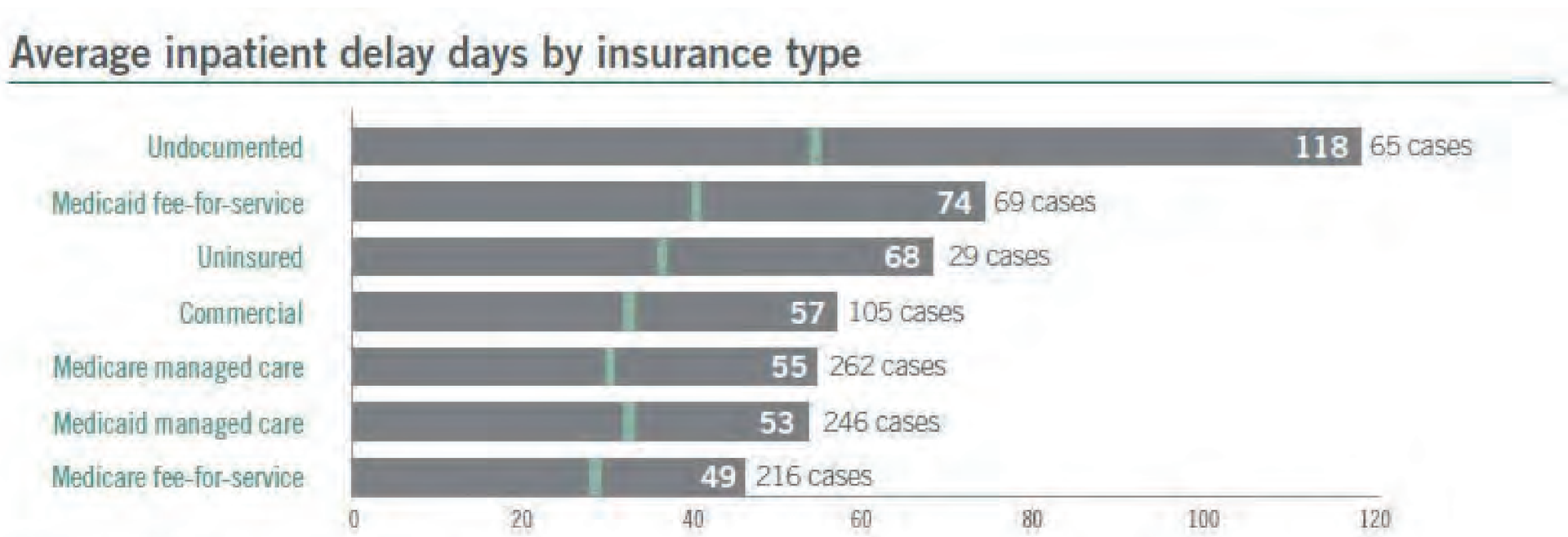
WHAT ARE THE COSTS?

Inpatient:

Fifty hospitals reported 992 patients experiencing discharge delays of more than two weeks between April 1 and June 30, 2022, at an estimated total cost of $167 million, or an average of $168,000 per case. Individuals who had an undocumented non-citizen status (most commonly uninsured or emergency Medicaid) experienced the longest average delayed days, followed by those with Medicaid fee-for-service.

$167 Million

(average of $168,000/case)



WHAT ARE THE COSTS?

Emergency Department:

Thirteen hospitals reported 123 patients experiencing discharge delays of more than four days in the ED at an estimated total cost of $2 million, or an average cost of $18,000 per delayed stay. Patients with Medicare managed care (Medicare Advantage) and Medicaid managed care most often experienced delays, while individuals with Medicare fee-for-service coverage experienced the longest average delays.

$2 Million

(average of $18,000/delayed stay)

Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

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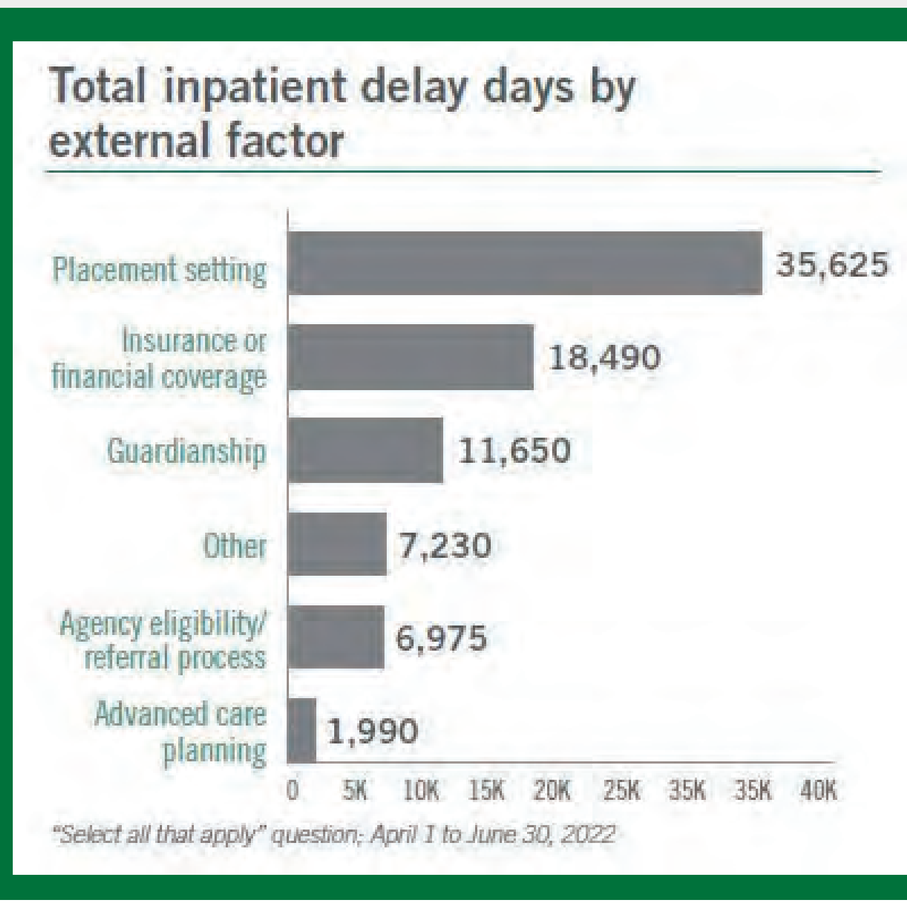
Solutions for Youth with Unmet Complex Needs

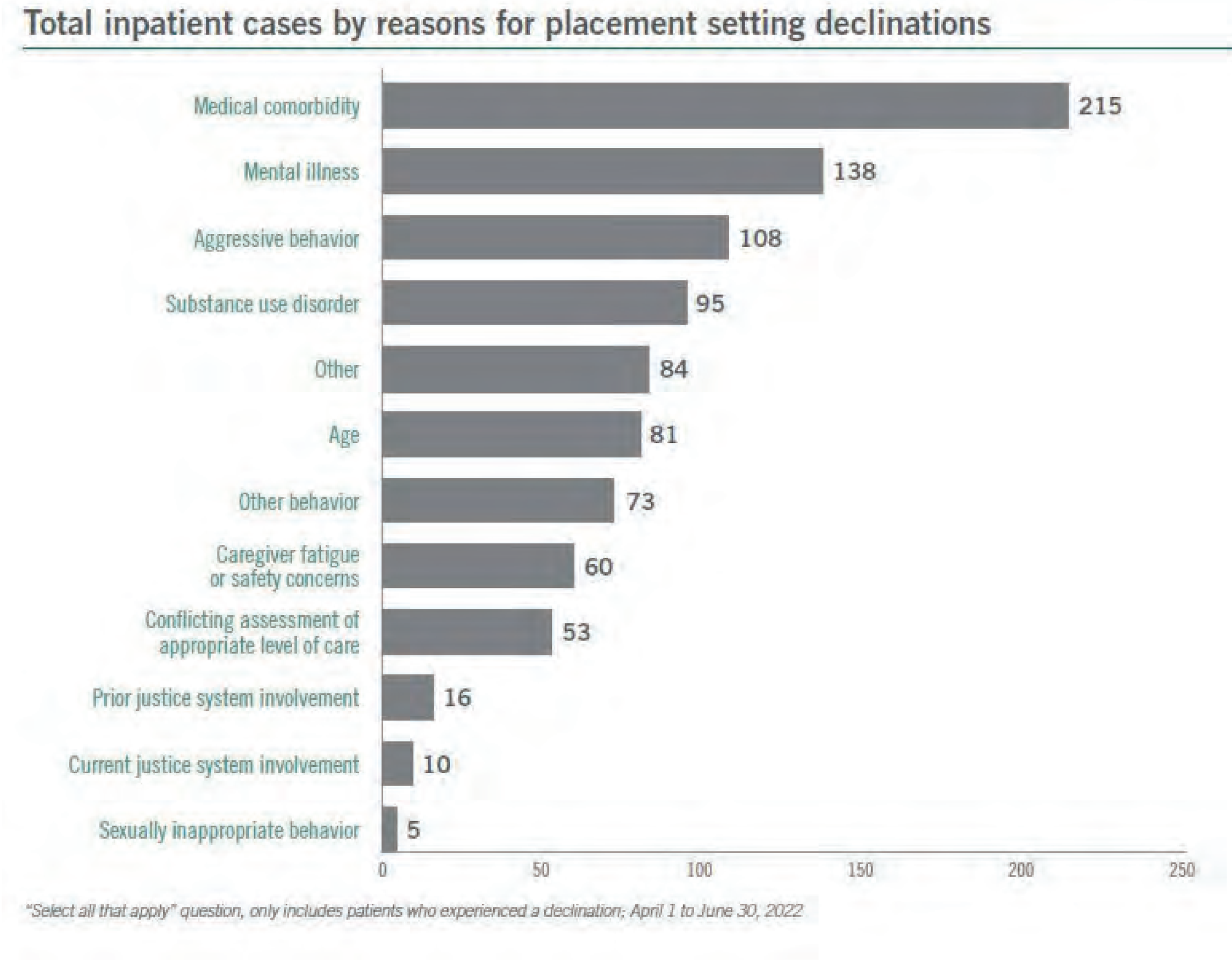
WHAT ARE THE REASONS FOR DELAYED HOSPITAL DISCHARGE? (Post-Inpatient)

WHAT IS CAUSING THE DELAYS?

Inpatient:

The most frequent contributor to discharge delay was identifying a placement setting. Individuals facing barriers to discharge due to guardianship and advanced care experienced the longest average delays. **The most common obstacle related to discharge placement settings was the inability of the placement setting to accept the patient.** Medical comorbidities and mental illness were the most common reasons for declination.





Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

Call to Action!

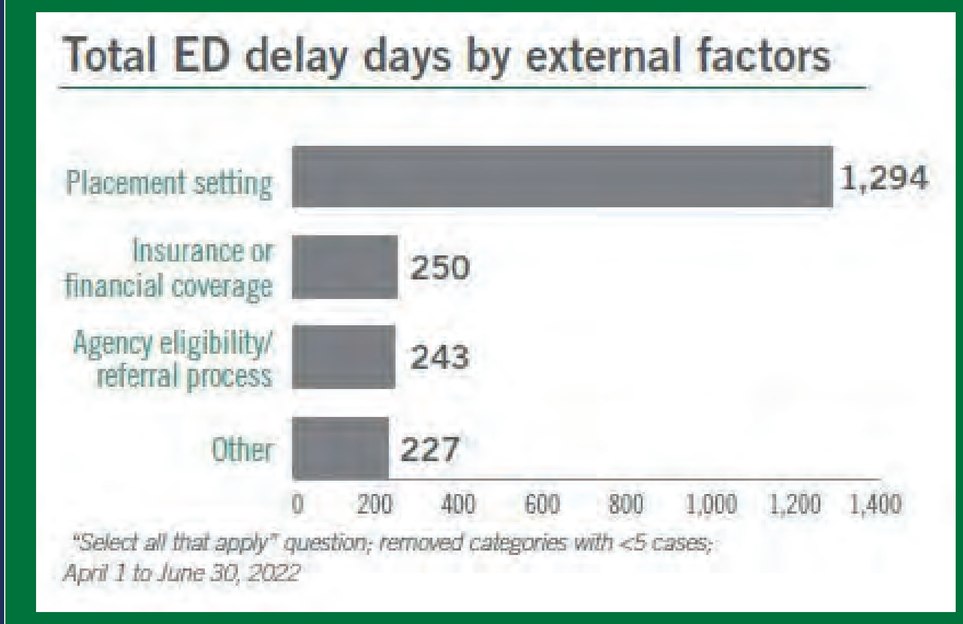
Solutions for Youth with Unmet Complex Needs

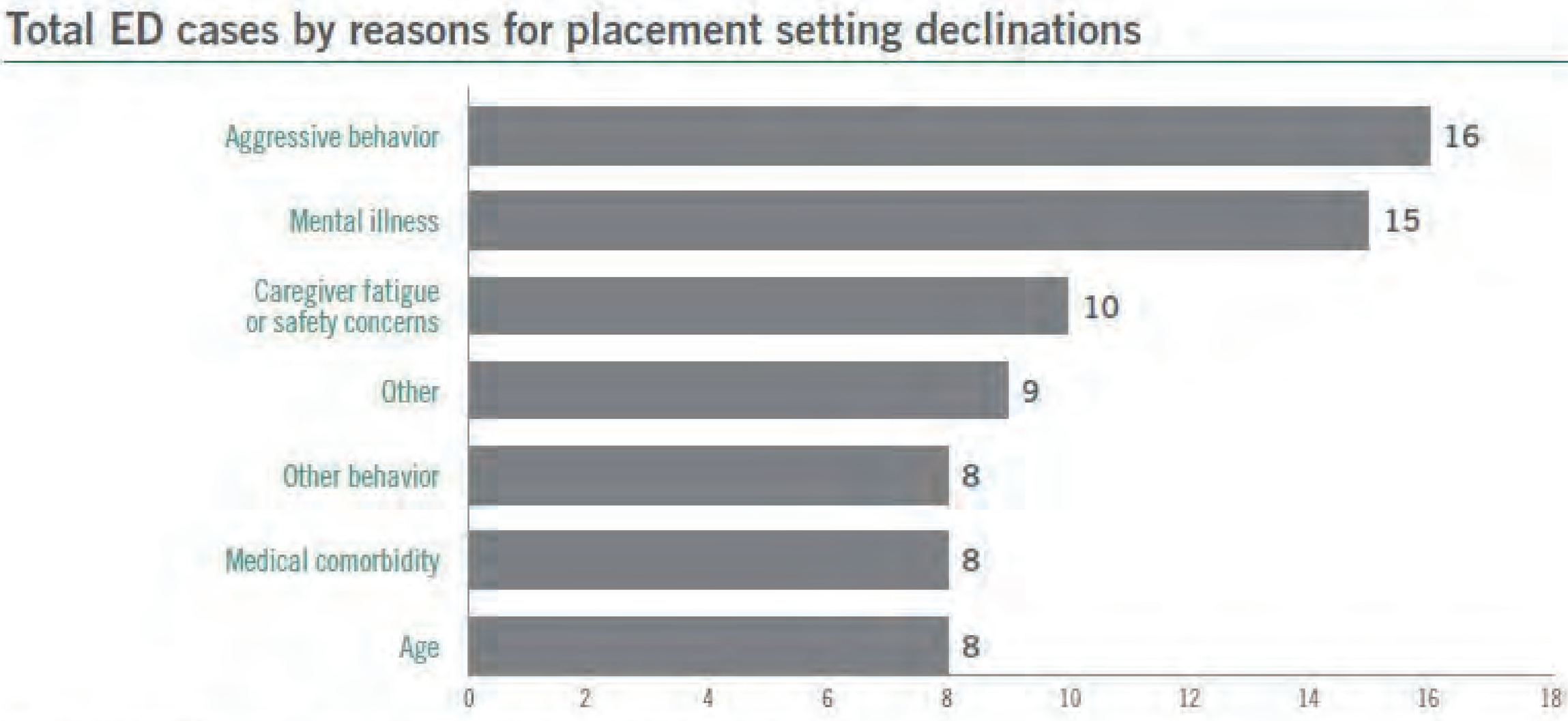
WHAT ARE THE REASONS FOR DELAYED HOSPITAL DISCHARGE? (Post-ED)

WHAT IS CAUSING THE DELAYS?

Emergency Department:

Identification of a placement setting was also the most common contributor to discharge delays in the ED. Individuals experiencing barriers due to state and local agency eligibility and referral processes for services and/or benefits had the longest average delay days. **Among those who were declined placement, aggressive behavior and mental illness were the most common reasons for declination.** Other external factors included challenges related to placement preference and engagement of patients or caregivers in the planning process.





Source: "The scope of complex case discharge delays in New York state" February 2023 - HANYS

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Solutions for Youth with Unmet Complex Needs

NO MORE WAITING

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.

PRIORITIZED RECOMMENDATIONS TO BEGIN ADDRESSING CARE DELAYS FOR NEW YORKERS WITH COMPLEX NEEDS:

- **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.

Source: "No More Waiting: Recommendations to begin addressing care delays for New Yorkers with complex needs" February 2024

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Solutions for Youth with Unmet Complex Needs

WHAT CAN WE DO -

to address **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 recommendations:

- Streamline and align multi-agency application and licensure processes.
- Remove unnecessary restrictions and increase flexibility.
- Identify and invest in complex care service models.

Immediate, non-crisis, transitional care recommendations:

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

Workforce recommendations:

- Invest in cross-disciplinary training and educational opportunities.
- Allow professionals to work at the top of their credentials.
- Expedite licensure and certification.
- Promote licensure and certification incentives.
- Expand telehealth.

Reimbursement recommendations:

- Evaluate and update reimbursement methodology.
- Enforce behavioral health parity.

Recommendations to increase visibility:

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

Source: "No More Waiting: Recommendations to begin addressing care delays for New Yorkers with complex needs" February 2024

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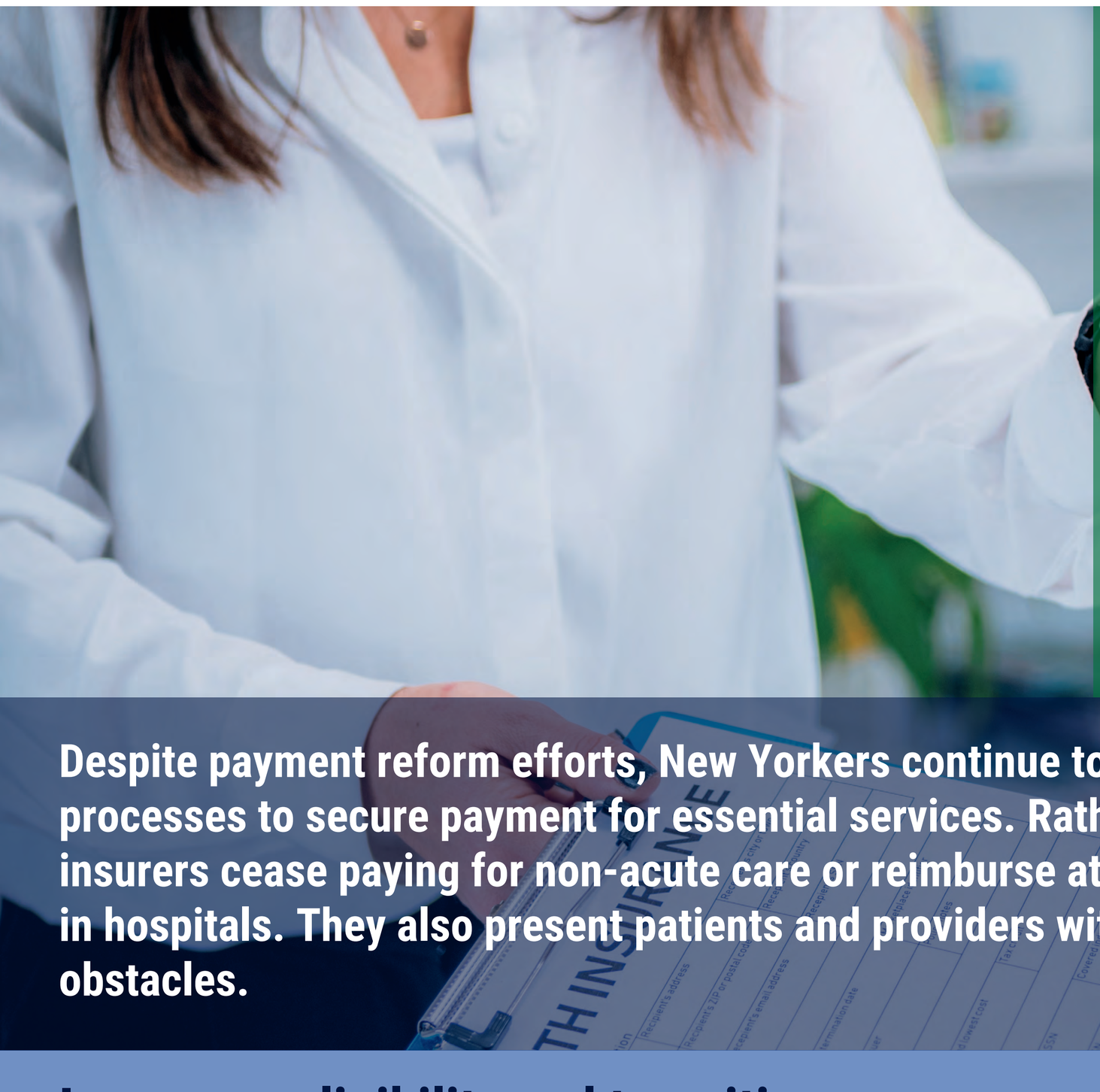
Solutions for Youth with Unmet Complex Needs



WHAT CAN WE DO - to secure 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.

Insurance eligibility and transitions recommendations:

- Expand Medicaid and the basic health program or establish a fund for individuals who require long-term care but are ineligible for Medicaid.
- Establish a fund to cover the cost of essential care during insurance transition waiting periods.
- Streamline Medicaid eligibility determinations.

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.

Prior authorization recommendations:

- Eliminate unnecessary prior authorization requirements.
- Reduce or eliminate prior authorization delays.
- Default to approval of coverage when health plans are non-responsive.
- Enforce and strengthen preauthorization requirements.

Network adequacy recommendations:

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

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.

Source: "No More Waiting: Recommendations to begin addressing care delays for New Yorkers with complex needs" February 2024

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Solutions for Youth with Unmet Complex Needs

WHAT CAN WE DO -

to ensure **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.

Interagency service coordination recommendations:

- Formalize agency-neutral guidelines to escalate cases with potential multi-agency involvement.
- Institute consistent rules and practices.
- Establish a single point of entry for all services and benefits.
- Establish an interagency initiative to assess and develop solutions to improve the eligibility and referral process.
- Leverage data to create visibility into the eligibility and referral process.
- Increase investment in and support for existing interagency taskforce groups and initiatives.
- Cultivate a shared understanding of and expectations for the eligibility and referral process.

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.

Source: "No More Waiting: Recommendations to begin addressing care delays for New Yorkers with complex needs" February 2024

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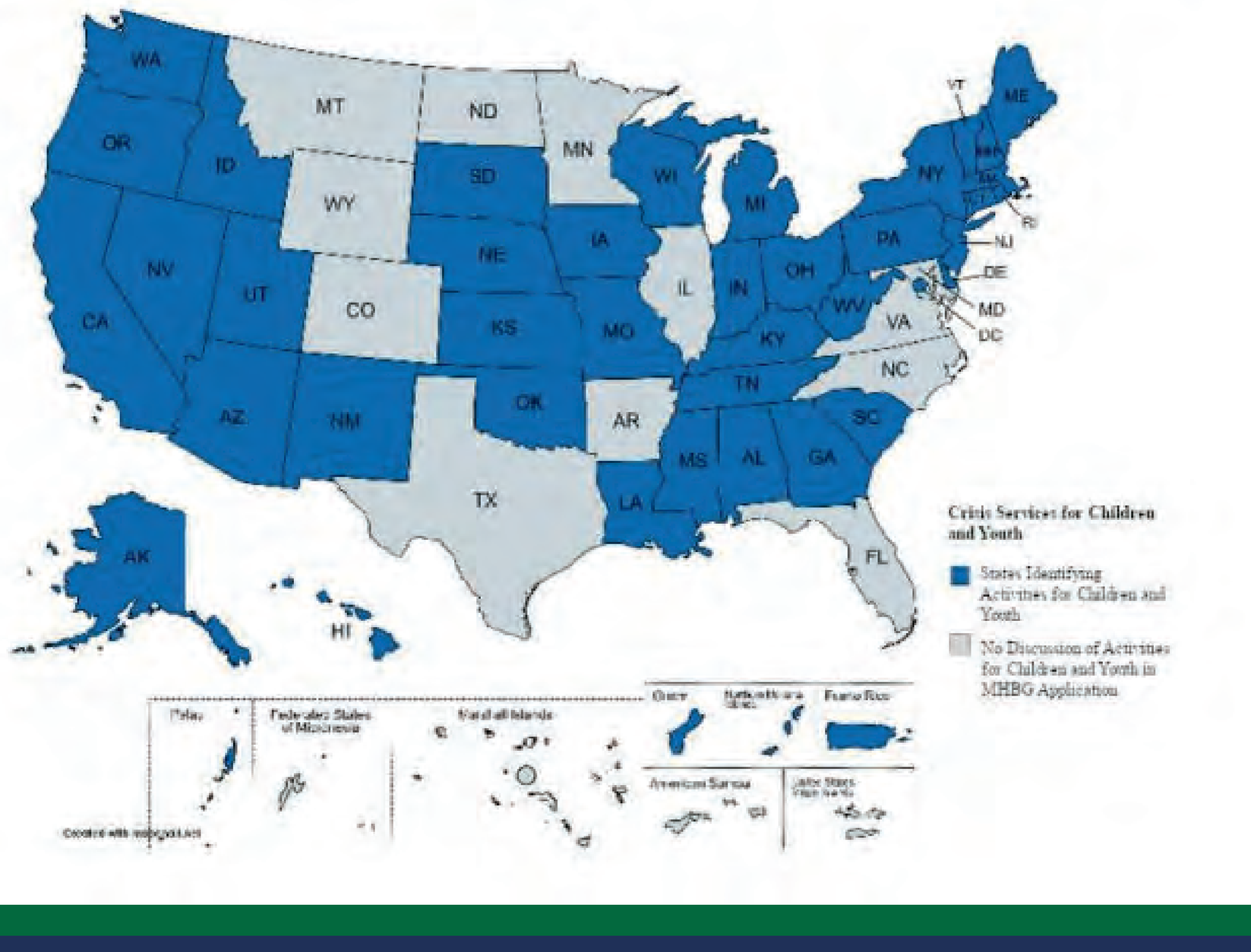
NATIONAL SNAPSHOT: CRISIS SERVICES FOR CHILDREN & YOUTH

Most (43) states and territories identified activities and/or needs related to improving crisis services for children and youth in their 2022/2023 Mental Health Block Grant applications, COVID-19 relief plans, and/or ARPA plans submitted to SAMHSA (Figure 11). Nearly half (20) of these State Mental Health Agencies (SMHAs) identified efforts to expand and improve mobile crisis services for children and youth (AK, CA, CT, DE, DC, GA, HI, ID, MA, MI, MO, NJ, NE, NM, OH, OR, RI, TN, UT, WA).

Figure 11: SMHAs Identifying Crisis Services for Children and Youth in MHBG, COVID-19, and ARPA Plans



Thirteen SMHAs are also investing funds in developing youth-specific and/or in-home crisis stabilization services (ID, IA, LA, ME, MA, MI, NE, NH, NJ, NY, OH, UT, WI). SMHAs also identified efforts to expand crisis services in school-based settings (CA, DC, ID, SD), divert children and youth from emergency departments (GA, ME, MO, VT), expand text and chat capabilities (AZ, NH, NJ, OR), and expand the crisis workforce for children and youth (AK, GU, LA), including an expanded use of children and youth-specific peers (KY, OR).

Source: www.samhsa.gov/sites/default/files/behavioral-health-crisis-services-snapshot.pdf

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PARENTS STRUGGLE TO FIND SUPPORT WHEN A CHILD NEEDS HELP OUTSIDE THE HOME

"That was my first experience thinking maybe they're right. I didn't know kids could have any type of mental health condition. Clearly, I am doing something wrong here."

~Randi Silverman, Parent, New York

reflecting on when she was told that her son was fine and that she was the one in need of treatment

"There is a theme that we hear often, that parents are to blame: they need parenting classes or need to learn how to handle their kids. Ultimately, my child needed to be the focus. She needed comprehensive, daily treatment."

~ Jennifer Zielinski, Parent, Idaho

"When Schuyler was 7, that was when I had tried absolutely everything — every pill, every doctor, every diet, every therapy, everything — and we were still at a point when home was unsafe . . . I realized then that everything we had been trying to do wasn't enough. If Schuyler had cancer, I would never think of myself as a failure if I didn't do chemo in my living room. I would never think of myself as giving up."

~ Christine Walker, Parent, Illinois

"Even within the profession there is a judgment that if your child is in residential treatment you must have failed, that you can't be a good parent if he's in residential treatment . . . It's about finding the place where [my son] can be successful. Him being successful and feeling successful is the most important thing."

~ Christianna Hale, Parent, Texas

Source: Kelly Burch. When Kids With Mental Illness Can't Live at Home. NAMI Blog. Jan. 31, 2018

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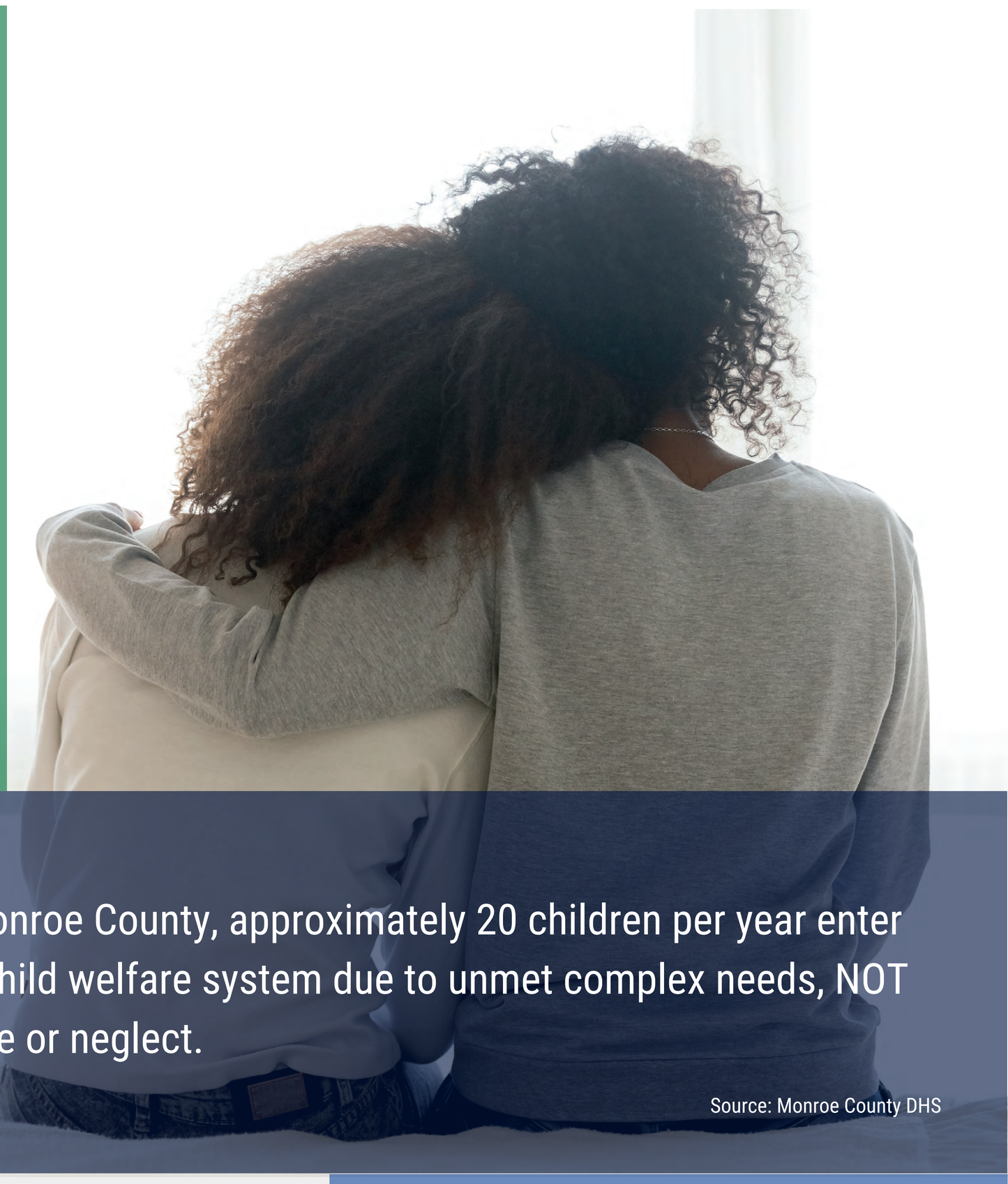
BARRIERS TO ACCESS CAN DRIVE ENTRY INTO FOSTER CARE



20 children per year

In Monroe County, approximately 20 children per year enter the child welfare system due to unmet complex needs, NOT abuse or neglect.

Source: Monroe County DHS

Nationwide, 10% of children in foster care (17,412 children) are entering the child welfare system due to “child behavior problem” or “child disability.”

Source: FY22 AFCARS Report, Children’s Bureau. May 2023

10%

Circumstances Associated with Child's Removal	Percent	Number
Neglect	62%	115,473
Drug Abuse (Parent)	33%	61,585
Caretaker Inability To Cope	13%	24,585
Physical Abuse	13%	23,958
Housing	11%	19,924
Child Behavior Problem	8%	14,280
Parent Incarceration	6%	11,821
Alcohol Abuse (Parent)	6%	10,686
Abandonment	5%	10,066
Sexual Abuse	4%	7,938
Drug Abuse (Child)	2%	4,089
Child Disability	2%	3,132
Parent Death	1%	2,488
Relinquishment	1%	1,874
Alcohol Abuse (Child)	0%	817

NOTE: These categories are not mutually exclusive, so percentages will total more than 100% and counts will be more than the total number of entries.

SOURCE: Adoption and Foster Care Analysis and Reporting System (AFCARS) FY 2022 data[2]

Barriers to accessing residential treatment and other services sometimes drive entry into foster care. For some children who are in out-of-home care, support and treatment in a therapeutic group home or residential treatment setting is the right service as the right time. Trending downward nationally, some children who are in out-of-home care receive support and treatment in a therapeutic group home or residential treatment setting. In 2012, 15% (57,592) of children in foster care resided in a residential setting on any given day, versus just 9% (33,728) of children in 2022.

Source: FY 2012-2022 AFCARS Reports, Children’s Bureau

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“We need to show these family members that they are not alone, and that help and hope are out there for each and every one of them.

~ Dr. Gary Blau,

Licensed Clinical Psychologist and former Chief of the Child, Adolescent and Family Branch for SAMHSA