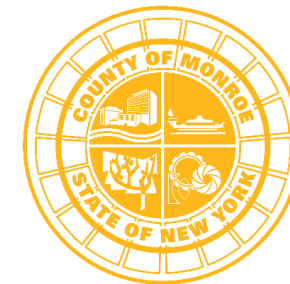




Quarterly Meeting

19 March 2025



Agenda

Working together for children with unmet complex needs



- Welcome and Introductions
- Preview – Cross-Systems Video
- Working Group Updates
 - Advocacy Workgroup
 - Future Workgroup Planning
- Guest Speaker – Meg Dygert, Senior Policy Associate, American Public Human Services Association (APHSA)
- Wrap Up

Working Group Updates

Working together for children with unmet complex needs



Advocacy Workgroup – Co-Chairs Stephanie Townsend & Heather Burroughs

Purpose - The purpose of the Advocacy Workgroup is to secure statewide funding, legislative action and regulatory changes that ensure children and youth with complex needs receive the essential care they deserve, when and where they need it. Our goal is to ensure all systems strengthen family connections, use integrated approaches, and address New York's growing crisis with sustainable solutions.



Advocacy Work So Far

State budget negotiations underway with budget due April 1

1

Letter to Governor

Broad asks raised at
September
Convening



2

Joint Letter on Budget

Signed by 13
organizations, sent
to 36 legislators



3

Budget Testimony

Joint Budget
Hearing on
Human Services



4

Meetings with Legislators

Members
meeting with
legislators

ADD
YOUR
VOICE!

Youth with Complex Needs

Giving Children the Care They Need, When and Where They Need It

March 2025

The Need

Children with complex intellectual and developmental disabilities and behavioral or mental health needs are being **hospitalized** longer than medically necessary and/or their families are surrendering them to **foster care** so they can receive care their families cannot otherwise access.

The Solutions

New York needs to (1) ensure OPWDD, OCFS and OMH work together to remove barriers so children can access community-based services, (2) expand residential and community-based services, and (3) build the workforce needed to serve these children and their families.

During a 3 month period¹

52 NY children

Experienced a "delayed discharge" from the hospital or emergency department due to issues such as lack of available care or residential options in the community, payment issues, legal barriers, and conflicting state regulations

This resulted in
5,110 days

of medically unnecessary
in-patient hospitalization

408 days

of medically unnecessary
emergency department stays



Over 1 year we can expect

208 NY children

to experience unnecessary
hospital stays totaling

20,440

in-patient days

and

1,632 ED days

The average cost per child or adult with complex care discharge delays is **\$168,000¹** for in-patient care and **\$18,000** for emergency department care. This does not include costs related to out-of-state residential placement of children with I/DD complex care needs when there are no beds available in NYS. A current case in WNY is costing the county **\$455,606** per year for the care and education of one child.

¹ The Scope of Complex Case Discharge Delays in New York State, Healthcare Association of New York State, 2023

Youth with Complex Needs

Behind every number is a child and a family...



"It's been traumatic navigating a system that often punishes families instead of supporting them."



"The system has failed us, and now my son faces an uncertain future, likely not finishing high school."



"We constantly search for staff to help care for our son. It feels like we're always starting from scratch."

"It's heartbreaking to see my son who has severe autism struggle without the help he needs to thrive in his community and at home."

Budget Opportunities

CFC

Fund \$25 million to **Council on Children and Families** for online data portal, staffing Interagency Resolution Unit, diagnostic services, and multi-system care coordination



Fund **Comprehensive Clinical Assessment Hubs** with at least \$2 million

ABA

Continue to cover **Applied Behavioral Analysis** services for Medicaid recipients



Increase **direct care service provider rates** for serving youth with behavioral health and I/DD needs

Legislative Opportunities



Improve **data** collection and transparency on boarding in hospitals, create a data portal to help with **coordination** of residential and community-based services, and strengthen **interagency collaboration** (bill forthcoming)



Allow family members of medically fragile children to become **complex care assistants** and be reimbursed by Medicaid under increased rates (S.4462)



Require **OPWDD waitlist** and placement report (S.4344)

Future Workgroup Planning



Working Group Updates

Working together for children with unmet complex needs



Systems & Services Redesign Workgroup – *Co-Chairs* ***TBD***

Draft Purpose - The purpose of the Systems & Services Redesign Workgroup is to identify and implement local and statewide solutions that support youth with complex needs and their families now while creating the infrastructure for a long-term integrated approach. Our goal is to help children thrive by keeping families together and providing effective services close to home.

Working Group Updates

Working together for children with unmet complex needs



Workforce Workgroup – *Co-Chairs TBD*

Draft Purpose - The purpose of the Workforce Workgroup is to build the skilled staffing needed to serve youth with complex needs through training, removing barriers to certification and licensing, and equitable compensation. Our goal is for youth with complex needs and their families to have access to timely, quality and consistent care close to home and for care providers to have the opportunity to build rewarding and sustainable careers.



Guest Speaker

Working together for children with unmet complex needs

**Meg Dygert, Senior Policy Associate,
American Public Human Services
Association (APHSA)**

*Addressing the Complex Needs of
Youth: A Call to Action*