



# Call to Action!

## Solutions for Youth with Unmet Complex Needs



In Monroe County and across the state, 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.

### OBJECTIVE

On September 16, 2024, Monroe County, in partnership with Senator Samra Brouk, Assemblywoman Sarah Clark, UR Medicine, Rochester Regional Health, and Hillside Children's Center held a Cross Systems Convening focused on concrete action to urgently generate and follow through on implementing practical solutions that will ensure youth and families have access to safe, appropriate, effective, and compassionate care and services that are close to home.

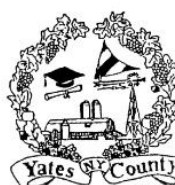
### CALL TO ACTION

#### Current Challenge

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. Community service options are limited and significantly understaffed. Children are entering foster care to access needed services.

No single system can solve this complicated challenge. By convening leaders across systems and in diverse roles, including families, we can work together to assess the issues, commit to shared next steps, and begin to transform the policy and practice infrastructure to improve the experiences and outcomes for youth and families with unmet complex needs. Almost 100 participants answered the call from the organizations represented below.

#### Opportunity





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## Solutions for Youth with Unmet Complex Needs



### SUMMARY

Convening attendees engaged in a data walk that included quantitative and qualitative local, state, and national data to build common language and shared understanding of the challenge's scope and impact. People expressed shock, sadness, and motivation for change after reflecting on the data presented, agreeing that families can't wait and noting that there is actionable data available. A Monroe County parent shared her recorded testimony with the hope that other families in similar situations would not have to resort to placing their child in foster care to access needed services. In small groups, participants discussed what currently exists to support youth and families with unmet complex needs and the existing gaps.

Participants also engaged in a panel discussion to learn from leaders in other states, including California, Virginia, Colorado, New Jersey, and Ohio, about how they are working to solve similar challenges. Specific examples of legislation, county collaboration, and statewide initiatives sparked ideas for the group. Based on ideas pitched by small groups, individuals who stayed for action planning created initial next steps for continued connection, communication, and collaboration. Themes were identified, and priority next steps included: scheduling a next Action Team meeting with those who volunteered to participate; creating a brief document with consensus recommendations to share with the Governor's office; developing strategies to communicate with the larger group and stakeholders; and creating pathways to implement key ideas.

Information from the convening is available on a landing page where we will continue to add shared resources. A Cross Systems Action Team was established to move ideas forward. <https://togetherthevoice.org/monroecounty/>

### CONSENSUS THEMES & RECOMMENDATIONS

SOLUTION	DESCRIPTION
Centralization	The group agreed that we need a centralized, unifying body with the authority and the responsibility to compel all the relevant statewide agencies to work together and simplify access to care. Current mechanisms exist under specific agency umbrellas, but no one system can solve this complicated challenge.
Flexible Funding	Funding and licensing silos have created unnecessary barriers to youth accessing the right care at the right time. Waiver flexibility and exceptions to regulatory limitations for youth with unmet complex needs would allow for braided or blended funding strategies that could better coordinate and connect families to care and services.
Increase Service Capacity	In addition to high-quality therapeutic residential capacity that can effectively serve children with complex needs, the group agreed that families need access to high quality respite care, more intensive in-home supports, skill-building, and care coordination similar to Bridges to Health, but for all youth and families in need.
Technology	The group agreed that there is a need for shared data across systems and that we need to develop technological tools to support collaborative solutions. Navigation apps, shared dashboards, and universal intake applications were a few of the suggested opportunities where technology could help fill gaps.
Invest in the Workforce	We don't have the workforce to meet the need. Not only do we need to incentivize and support program staff, the group agreed that there is a gap in training and expertise in working specifically with dual diagnosis young people that have intellectual or development disabilities coupled with mental health challenges and aggression.