



The Young Leaders and Advocates Network [YLAN] is a statewide network run for and by young people with disabilities. YLAN is dedicated to uniting and empowering young people across the state. We ensure young people are authentically and meaningfully involved in all decisions that affect us. Together we change systems so young people get the support they need with the respect and dignity they deserve.

YLAN hosted a state-wide event in partnership with NYS Office of Mental Health [OMH] over the summer that included young people with cross-system, cross-disability experience who provided feedback about services and supports they have experienced as a young person. YLAN staff attended the Attorney Generals Buffalo Mental Health event on January 18, 2023 and wanted to highlight those points which young people themselves have also given feedback on.

#### **ACCESS**

Young people report lack of access to care before a crisis arises. They reported begging for services and their parents and caregivers having to fight tooth and nail to try to get them support only to be faced with long waitlists which in turn left them no choice but to go to the ER when they naturally ended up in crisis due to lack of access. Overall young people felt they couldn't get their needs met until they were in crisis and there was no other choice.

Young People are sending a clear message - More beds isn't the only answer. For youth, this comment includes the focus on residential placement. What they need is programming that supports full community integration, with programs similar to the Personal Recovery Oriented Services [PROS] that are available for adults, but not young people. Many young persons who struggled in CPEP could be better served by partial hospitalization programs, such as are in Rochester.

As part of the Governor's plan, young people would be seeking increased funding for youth programs for hospital diversion, but also Restorative Justice (since a strong point made in the hearings was about reducing criminal justice involvement in mental health crisis.) This has to include educating first responders on the use of and referral to those programs, and stop their contribution to youth recidivism.

They are looking for Peer services being available when they best need them – even 24/7. Especially, YLAN heard from young people that integrating the peer perspective in state “Warm-line” programs (that provide telephone support prior to crisis).

Young people reported that having the ability to access multiple services in one place was helpful for their family to receive care but having choice in this was of equal importance. It reduced stigma as it was right at school where everyone was already. Hours outside of school were noted as especially important for access.



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In adding on this point. School Based Mental Health clinics are HELPFUL!. Unfortunately, not every school district has implemented them. Many young people indicated this was their only access to services, especially in rural communities.

### **SERVICE EXPERIENCE**

In our event last summer, there were some statements made that fit very easily into the discussion at the hearing. Young people believe that the system needs to “treat them [when hospitalized for their mental health] with compassion and grace” and that it needs to be the “same positive wraparound care with supports just as if they were on a medical floor.”

Many young people have multiple diagnoses alongside the one for mental health, including substance use, physical, developmental, and intellectual needs. These young people experience intersectionality in their daily lives but services and supports in the community fail to serve them because they still are siloed. For example, young people get denied access to care with OPWDD because they have mental health experience, and people with Autism Spectrum Disorders are denied mental health treatment. They experience extreme differences in treatment for their physical disabilities than when they need care or hospitalization for their mental health.

Young people know that the wraparound is effective, yet we continue to fall short in supporting the resources necessary to support the model. At no point should a young person with multiple disabilities be kept in a hospital bed due to lack of an appropriate placement. The system needs to remove the siloes and fulfill the promise made with the wraparound model, includes billing for multiple services during the same clinical visit.

At no point though, should we be continuing to keep young people in hospital settings due to lack of an appr

### **WORKFORCE**

Lastly, many comments were made at the hearing about the “staffing crisis,” and many calls were made for increased Peer services. Young people who have had experience with Peers believe strongly in the model, but also feel that role of peers is being misused, due to the lack of availability to other professionals and services. Resources need to be put in place to support the entire network of providers, so that peers can be the part of the solution without burnout. Peers should be supported as a level of service on their own, and not just a temporary fill in for professionals with long wait lists. Youth peer advocates report that the authenticity of Peer services was starting to be at risk, since putting them in with clinics and schools appears to limit peer activity to only what the clinic or school wants, rather than what the youth need.

Events like the one over the summer where we gather young people together and meet them where they are at as peers and establish a common ground to promote change together to bring feedback to a higher level is needed in deciding where this funding goes for young people. Without including their voice in deciding priorities we are excluding them from decision-making in their own lives and that is inhumane. YLAN is an asset to pushing in or gathering young people do provide feedback on services and supports they are engaging with. We would be happy to be a support in the future in aiding the AG office in authentically involving young people. Just feel free to contact us using the information above.