

# CSOC Stakeholder Convenings: Participant Survey Responses

## Promote integrated health and behavioral health

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### Strengths:

- The system is led by and full of people who genuinely care more about children and families than bureaucracy. The vast majority of CSOC staff and partners are motivated, intelligent, and family-centered people who do their best to connect families to services and struggle with the difficulties created by limited resources.
- Caring leadership and personnel commitment to developing a broader vision to address DCF priorities & the needs of children with disabilities.
- We are the only state-wide system of care in the country.
- The collaboration among CMOs with other child-serving systems like juvenile court, DCP, community providers, and education has transformed the lives of youth in NJ.
- Collaborative approach, family driven.
- It has created a more coordinated system of care to serve children and youth with serious emotional needs and also has a strong community-based approach.
- Current strengths of the Children's System of Care include the progressive movement towards open communication and informed collaboration amongst all youth serving systems.
- Earnestness to reevaluate provided services within the scope of current trends and needs of New Jersey youth.
- CSOC's openness to listen to youth and family voice of lived experience.
- Strength-based, child and family centered.

### Challenges:

- Need for broader perspective on the challenges in raising a child with disabilities.
- Need for enhanced understanding about the nature of developmental disabilities; the interaction between dd, mental health & behavioral needs.
- Increased flexibility models of care management.
- Poor communication between service providers. Lack of appreciation for the value of services among service providers.
- My impression is that there are still issues in serving children involved in more than one system, i.e. foster care or juvenile justice, and that alignment is still problematic. I also believe that there is a real gap in services for children age 5 and under. Finally, I have concerns about limitations on how long services may be provided that depend more on established timeframes rather than individual need. However, this is my impression based on anecdotal information.
- Limited integration of developmental disability and behavioral health system.
- Disconnect with FSO/CMO and access to them.
- Poor support for kids under age 4.
- Transition to adulthood weak.
- More training is needed in IDD Services, co-occurring and addictions services.

### Case Examples:

- Initial call to M2M on 8/8. - 16 yr son (C) with diagnosis of bipolar, ADHD, intellectual disability, history of eloping, multiple out of home placements since 2010, attends out of district school placement. E first called M2M on 8/8. Her son, C, ran away from his group home. CMO (Passaic County) involved (son DD eligible w/ family supports via PerformCare), police assisted with search. Next day son was located and unharmed. E. brought him home to live with her family. CMO promised to get an emergency OOH placement and secure in home supports during the interim. It wasn't until around 8/28 (about 20 days later!) that CMO secured an in home therapist (twice weekly for 2 hours each) to work with C. The following week CMO had an in home mentor for C (twice weekly for 2 hours each) – in total only 4 hours of in home support weekly. C. continued to elope from home, had patterns of stealing from family members and stores and E. continued to call the police. DCP&P has escalated matters and contacted Executive Director of CMO to get much more supports and expedite an OOH for C. Additionally, C. was supposed to start school on 9/3 but school district had issues with getting a bus to pick him up to bring him to his out of district school. Only on 9/12 did bus arrive to take him to school. CMO Supervisor and School district CST case manager to meet with E. on 9/13 or soon thereafter. C may possibly go to an out of state residential school to best meet his needs but nothing's confirmed yet.

### Recommendations:

- Provide training and ongoing support around education and health advocacy.
- We need to reshape the philosophy of CSOC from a disease model to understanding the impact of complex trauma and critical importance of including permanency work as part of the treatment model, as many kids have reactive attachment disorder. The providers can do life connections, search, engagement and transition work if we are given increase in rates. When a child is stepping down to family the provider clinician should stay connected to the family until the child and family is through the reintegration phase.
- Expand CSOC to provide services to younger children. In addition to reaching an underserved population, it can be more effective and cost-effective to address issues at an earlier stage.
- Establish clear protocols about coordination among agencies when a child is known to more than one state system. These may already exist and I am just unaware of them.
- Continue to stress the importance of connections, relationships and collaborations, to try and move past the barrier of stigma / denial / “not my kid” in order to connect people with appropriate and helpful resources.
- Mom 2 Mom or a system with the same capacity should be the front end to a revamped FSO system that does focused family support and hands off to us for telephonic peer support and case manage to coordinate care.
- Early intervention line and system should be changed to be an integrated care approach with pediatricians and DOE should start to join the CSOC as they have been absent or horrible.

## Build capacity to deliver evidence-based and best practice interventions and services

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### Strengths:

- The wraparound value driven approach to engaging youth and families: Strength-based, individualized, culturally competent, team-based, youth/family voice and choice, collaboration, use of natural supports, community-based, unconditional care, and outcome-driven as well as the implementation the Nurtured Heart Approach and Six Core Strategies.

### Challenges:

- Speaking directly about the I/DD population, there seems to be limited knowledge among leadership regarding their specific treatment and support needs. Experts in evidence-based practices and family resilience for the I/DD population throughout the state have and would continue to freely offer recommendations to inform CSOC's service delivery models to meet acute, short-term, and long-term needs. The efforts to date have been productive and could be expanded.
- Extreme lack of substance use providers for youth and young adults. Also youth must agree to commit to substance use services. Wraparound model is not always practiced, less often than more. Credentials for providers such as parent coaches, life coaches etc; What type of credentials do they provide for providing services? Systematic data collection is poor. Agencies resort to keeping paper documentation of all data for accurate reporting.
- Providers not emersed in the NHA approach.
- Punitive responses to behavior.
- There are multiple barriers to accessing substance use disorder specific services for youth. These include barriers created by screening challenges, lack of awareness specific to existing policy and resources, geographic barriers, reimbursement challenges that lend themselves to increased mental health referrals and decreased SUD referrals, social determinant factors such as lack of transportation, motivation to receive treatment, and most prevalent, stigma.

### Case Examples:

- Crisis Stabilization Homes – While well intentioned, the design of this service line missed the mark. These homes were designed to be 90 to 120 day stays for children with I/DD in behavioral crisis and required some services that were unnecessary and overburdensome as well as insufficient amounts of other services. Most experts agree that 90 to 120 days is an extremely short period of time to assess and treat a child in crisis while at the same time having that child attend a full day of school and providing him/her with ancillary services.
- Intensive I/DD IOS – It is our understanding that this OOH program was intended to be a specialized stabilization unit for children with severe challenging behavior. This RFP seemed to be an attempt to replicate other existing and effective neurostabilization units, yet with a lower reimbursement rate and the addition of unnecessary services and requirements. We are optimistic that CSOC's Request for Information (RFI) on these services earlier this year yielded recommendations that will be incorporated into future RFPs to improve the effectiveness of this service line.
- ABA I/H – This program is designed to meet the needs of I/DD children with challenging behavior in their homes by providing approximately 12 hours of ABA services a week. Most individuals with this level of need require much more than 12 hours a week and the existing reimbursement rate for these services makes it unsustainable unless the provider finds staffing efficiencies that would most likely diminish the quality of the service to the child.

### Recommendations:

- Provide training and ongoing support around trauma-informed care, health disparities, cultural reciprocity.
- There is a plethora of research available on best practices in treating and supporting children with I/DD, and we would respectfully suggest and encourage the Division to reference this literature as they move forward to improve these service lines.
- We need to revisit the earlier model of Treatment home LOC that would enable a teen to stay with the family when there is no viable family placement and the goal is now moving toward independent living. Therapeutic efforts would transition to finding life connections that will stay with the youth as life coaches/mentors and preparation for transition to adult hood. Legal permanency would still stay the goal,

but we will also do concurrent planning to support the teen if legal permanence does not come through. We developed a three tier model years ago.

- Trainings: NHA training for all stakeholders, Trauma reaction training, Engagement of high risk youth training

## Enhance CSOC capacity to ensure equitable access

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### Strengths:

- FSOs, CMOs, Youth activities, and mobile response available to families throughout the state.
- Family support available not just to families of children with the most significant mental/behavioral health needs.
- Having a single point of entry.
- Some respite support.
- Most recent data (August 2019) from CYBER shows 90% of youth served through CMOs are being done so in the home/community. The team-based, collaborative approach as well as the expansion and development of community-based resources to meet the needs of our youth and families has supported their success in the community. And in the process has made us less reliant on more restrictive (and out of state) facilities and programs.
- Wraparound model prepares families to be successful in their journey inclusive of all family members. Services are coordinated according to individual family member needs. Natural resources are highlighted as positive family supports. Families are served according to level of need. State wide Nurtured Heart Approach initiative conforms to a common language and approach to working with families. No cost for services.
- Performcare, the behavioral health expertise, new leader.

### Challenges:

- Uneven nature of FSOs, CMOs, mobile response.
- Need for stronger youth support around self-advocacy.
- Need for stronger capacity for both education and health advocacy for children, youth and families. Insufficient step down supports.
- Need for greater diversity in staffing.
- Need for enhanced capacity to provide trauma-informed services and supports.
- Still racial, immigrant, language, etc. gaps in services and outcomes.
- Confusion with applications.
- Access to services and supports for youth with DD/ID. Although it is a relatively smaller percentage of the youth we serve, it tends to absorb more of our time given the intensity of the youth's safety needs and the family's sense of urgency.
- There are also challenges to accessing community-based services for youth with DD/ID. Because of the lack of availability of providers in one area, it may require a provider to travel long distances to serve a youth and their family. There can also be a lack of consistency with providing a service to a youth with DD/ID. The provider may not be able to fully staff the number of hours identified in the Functional Behavior Assessment or they may not be able to continue the service to completion for a variety of reasons Access to services through CSOC.
- CMOs have been periodically receiving reports from FSO and community members that youth who have gone through the assessment process and seemingly need the CMO are not gaining access to the CMO.
- Implementation of services is often a long process from the time a family calls PerformCare.

- Lack of clinical providers in the community creates a longer wait list. Lack of community awareness regarding CSOC services.
- CYBER dashboard information is often incorrect. PerformCare often dismisses calls if a diagnosis is not given on intake call. Quite often families are transitioned from CMO services and other providers are not notified.
- It can take several weeks to a month or more to implement services for a youth. Schools, hospitals and health centers are not aware of CSOC services or have little knowledge of services available to families.
- Accessing services appear to be more difficult for children who do not have a parent to advocates for them.
- The perceived lack of support and difficulty in navigating the Perform Care System.
- Difficulty in placing youth in treatment; specifically youth with IDD diagnosis, or previous treatment episodes in CSOC contracted providers.
- It has been continually challenging to statistically capture a clear picture of utilized services. The CSOC CIACC Dashboard only provides a snapshot of youth within the community. Youth who do not enter treatment under the CSOC are not reflected, as well as even if a referral comes through Perform Care if services are not paid for by CSOC then the admission is not captured within the data. In addition, youth age 14 and over have the right to request that the substance use findings not be entered into the Cyber database also causing them not to be captured.
- Lack of standard of care by county with all services as they vary greatly, limited resources in south jersey.
- Rates need to be studied to ensure adequate workforce capacity which equates to positive outcomes.

#### Case Examples:

- A typical example might be a youth with DD/ID on the crisis screening unit, but they are “stuck” have nowhere to go. Efforts to identify a psychiatric inpatient unit are unsuccessful and/or there are no crisis stabilization beds available. There are also long waits (sometimes one year or more) to access an out of home treatment program.
- In situations in which youth with DD/ID are “stuck” at the crisis screening unit or are experiencing long waits for accessing out of home treatment, parents/caregivers are frequently advocating for their children with CMO Executive Directors, with CSOC, or with other components of the state government. Most likely CSOC staff are already aware of a specific youth’s situation.
- Care giver called Perform Care requesting services for two youths, more than a month later received a letter stating that one of the youth was not eligible to receive services, when care giver contacted Perform Care again was informed that the reason why one of the youth was not eligible to receive services was because the youth doesn't have a diagnostic. Care giver was suggested to call Mobile Response.
- Data for initial visits and CFT visits completed vs invited can be provided. Example: For the month of August: Of 52 new youth referrals FSO received 3 Initial Visit invites by email from CMO but attended 12 with CM and 18 without CM by communicating with families directly. FSO received 10 CFT invites and attended 7 as reported by CMO in CYBER. FSO reported 11 CFT's attended. Clear miss on data collection and reporting.
- A juvenile who resided in Little Egg Harbor who was unable to secure transportation to treatment. The juvenile’s family did not have reliable transportation, and Medicaid transport denied services due to the juvenile living more than 20 miles from the only CSOC contracted treatment provider available. Generalized to all youth in NJ, Logisticare (Medicaid transport) does not travel more than 20 miles from a juvenile’s residence to a treatment provider. While there is an appeal process to have the extra mileage approved, often times the community and providers are not informed. Also Logisticare requires two business days to secure an appointment for pick-up, further delaying access to assessment and treatment services.
- With a limited number of CSOC contracted providers available, it has become a challenge at times to place youth who may have had previous treatment episodes with CSOC contracted providers. Specifically I consulted on a case where the juvenile was justice involved, had previous unsuccessful treatment episodes delaying the youth’s access to services. Fortunately SUN was able to assist with linkage to services as the

juvenile had private insurance which provided increased options of treatment providers outside of the CSOC.

- 16 year son (C.) with severe autism and history of self injurious behaviors, property destruction, hurting others had limited life skills in home behavioral therapies and numerous ER hospital visits – CMO/FSO/DCP&P involvement. In 11/16 – Hudson County CMO secured an OOH (short term behavior stabilization program) for C. He was discharged back home in 4/16 (original authorization was for C to be at his OOH for another month) with a plan for a lot of in home behavioral supports along with C attending a different out of district SPED program which better met his needs. C started his new school program shortly after he returned home but the CMO didn't actually get in home supports (ABA therapists) in place until about 3 ½ weeks later and C regressed behaviorally. Once in home therapists started (up to 15 hours weekly) with C, he started to improve and K got parent training.

### Recommendations:

- Strengthen the role of FSOs in the care management process.
- Flexibility and resiliency within the department for providers to be able to work within their contract to support the youth and address individual needs even if it means to go above the contract requirements or under the contracted requirements. If there is no COLA or resolution to the Budget for a wage adjustment could CSOC offer alternate monies to providers to retain licensed staff and also for “direct support staff” as a state stipend to attend a certification program/ series of workshops to create a career path in the field that the provider does not only have to fund. (eg we have to pay staff to attend workshops and trainings and then also pay alternate staff to cover shifts)
- Support a CSOC, Provider, CMO, CPP workgroup (all together) to establish best practices for working together and collaborating to support youth/families in care. There are often separate workgroups, but not one that comprises the key players often involved in a youth's care.
- There needs to be an integrated treatment approach that includes an identified birth /kin/adoptive family in the therapeutic process from the intake stage and throughout. When there is no family willing/able we need to identify kin, relatives etc. to begin participating in treatment so child has a sense of hope for the future. Children and Youth served by DCP need to have access to full array of CSOC services as soon as there is a clinical diagnosis or identified behavioral pattern indicating that child is at risk of harm in current family placement.
- Review approach to children with DD and their families. Develop models of support/respite that are "behaviorally informed" but are not treatment. Review & enhance role of CMOs
- There is a need to build up the skills and knowledge of those serving youth and families through CSOC in the area of youth substance use. We have also experienced conflict with substance use treatment providers over implementing wraparound/system of care values when engaging youth and families.
- The Ocean County CIACC produced a white paper outlining their recommended solutions to address the needs of youth with DD/ID and their families. The CMOs have been conducting regional work groups to also identify recommendations to address the needs of youth with DD/ID and their access to services. Both documents have been presented to CSOC.
- Build up capacity for clinicians with LCADC who treat adolescents. Include language in contracts with CSOC that all providers agree to adhere to wraparound/system of care values.
- Improve data collection systems.
- Provide more in depth training to call center personnel.
- Create incentives for providers to do business with CSOC to increase the provider network available to families.
- Increased funding for transportation services or the addition of school based programs.

**Document Title**

- Expansion of CSOC contracted providers to provide increased treatment provider options, as well as increased geographic access.
- Use the stakeholder forum and subcommittees to discuss and recommend rates.
- Have DCF seek an immediate rebalancing of the psychiatric assessment rate.
- Hire the Boggs Center to do IDD training for the entire system to raise their awareness.