

June 26, 2024

Assistant Commissioner Mollie Greene
Children's System of Care
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Assistant Commissioner Greene:

Per the 1993 Family Support Act, the New Jersey Regional Family Support Planning Councils (RFSPC) were created. There are 10 regional councils covering New Jersey's 21 counties. NJ RFSPC provides a venue for parents and family members of individuals with Intellectual or Developmental Disabilities (I/DD) to exchange knowledge and information about family support services. Members advocate for families and individuals with developmental disabilities on issues directly impacting their lives.

We appreciate this important opportunity to share our feedback on the Contracted System Administrator's (CSA) Scope of Work (SOW). New Jersey is known for its public behavioral health services, especially for various in-home supports and 24/7 access to the CSA. The CSA has a critical role, especially as a "**front door**" for parents or primary caregivers of children and youth with I/DD who anxiously, and often desperately, seek support and services. We strongly believe that all front doors to the state service system should be **welcoming, easy, and streamlined**. The CSA also must **listen, understand, and respond** to the needs of child, youth, and their families efficiently and timely. The philosophy and principles of person- and family-centered practice must be fully infused in every aspect of the SOW.

It is also important that the CSA **collect meaningful data** and **monitor the quality and effectiveness of services from a youth and family perspective**. The current SOW includes collecting qualitative data, but more robust outcome measurements from youth and family/caregivers are needed. As illustrated in [this news article](#), children and youth with severe behavioral needs and their families suffer from a lack of specialized services and long waitlists. The CSA can contribute to improving the service delivery system by gathering stories from people with lived experience so that CSOC and CSA can use them to identify the service gaps and create improvement plans.

We respectfully submit the following suggestions to enhance the above-stated goals and objectives.

3.17 QUALITY AND OUTCOMES MANAGEMENT AND SYSTEMS MEASUREMENT PROGRAM (page 67)

Add individual outcomes in the individual electronic record. Outcome reports are summarized. Need a way to not lose the personal connection between the individual and CSOC. Consider including a family statement in the individual electronic record. Also a satisfaction survey: 1) how easy was it to get services?; 2) were services offered what you needed?; 3) how long did it take to actually receive services?; and 4) Did the vendor successfully provide the family with the benefit information and contact to obtain services through insurance? Are they alleviating family need to jump through hoops for benefit approval? Outcome reports should include a summary of the survey.

3.2 SERVICE DELIVERY (page 34)

A. 8. (page 34) re: Presence at and participation in community and statewide meetings

Offer a combination of in-person and virtual meetings. Provide a summary of questions and issues raised and answers and solutions offered to CSOC. Provide a quarterly summary of community events.

3.3.2 TRAINING (page 38)

3.3.2.C. Add the Regional Family Support Planning Councils as one of the “family advocacy groups in New Jersey.” For the I/DD training, seek the Boggs Center on Developmental Disabilities’ expertise and support

3.5.2 CUSTOMER SERVICE (Page 47)

3.5.2.16 (Page 47) – “Provide general assistance and information to families seeking an understanding of how to access care in either the private or public sector for their youth with emotional and/or behavioral challenges (e.g. how to get an evaluation for a child). Provide information to families about resources available through a Family Support Organization (FSO);” Add “I/DD and substance abuse treatment needs” after “...for their youth with emotional and/or behavioral challenges”

3.5.3 WEBSITE (page 49)

Include Regional Family Support Planning Councils on website 3.5.3 Website – community organization. <https://njcdd.org/the-regional-family-support-planning-councils/>

3.5.5. MEMBER HANDBOOK (page 51)

Require approval of CSOC before publishing. Recommend Vendor form a committee with youth and families with lived experience to review the handbook. Handbook should include services listed in 3.6.1.3.

3.6.1 UTILIZATION MANAGEMENT REQUIREMENTS (page 53)

Collect meaningful data to monitor and improve service delivery such as:

- How long Vendor took to respond to a request
- How long to assign to CMO,
- How long CMO took to identify a Service Provider,
- How long for Service Provider to actually provide service,
- How well did Service Provider provide service
- Did they actually show up, and
- Did they address the issue

3.6.1 (I) 4. UTILIZATION MANAGEMENT REQUIREMENTS (page 54)

“Continued Stay Reviews...” Replace ‘Appropriate’ with ‘until successful completion’ or if no additional benefit can be achieved. It must have a consensus of family.

3.6.1.5.3 SERVICE DENIALS, REDUCTIONS, AND TERMINATIONS (page 58)

Need to define under what circumstances services can be terminated. What recourse do families have?

3.15 CARE COORDINATION REQUIREMENTS (page 63)

Section 3.15 (D) 5. Need to identify issues which affects delivery of services. Recommend that this be (a) in this section, replacing ‘Discharge Planning’.

3.17 QUALITY AND OUTCOMES MANAGEMENT AND SYSTEMS MEASUREMENT PROGRAM (page 67)

Develop more robust outcome measurements, in particular qualitative data, to collect feedback from children, youth, and family/caregivers to assess the impacts of services and support and identify service gaps

3.19.2 RECONSIDERATION (page 71)

Need to include the family voice or perspective in the reconsideration process and conclusion.

3.20 SUPPORT FOR NETWORK DEVELOPMENT (page 74)

Include a minimum of two-week notice to all users and CSOC c-suite for schedule maintenance of MIS. Need immediate notice to users and CSOC c-suite of system total or partial unavailability.

Service unavailability is an increasing issue. In addition to data provided by the Contractor on the geographic and type of service, should they be solicited for possible solutions? Broader question is will CSOC participate in a proactive attempt to fill the service gap?

Section 3.20 (B) 2 – replace ‘Pay attention’ with provide resources to address linguistic cultural or other communication barriers.

3.22.1 SECURITY PLAN (page 75)

Replace ‘for the proposed solution’ with ‘which addresses egress and ingress of physical plant and offices and MIS’

3.23.1 MIS OVERVIEW (page 78)

Include identification of major improvements to the MIS to address recommended to address potential obsolescence.

3.23.14 MIS SUPPORT AND MAINTENANCE PLAN (page 91)

Create Performance Incentives/Disincentives for the following key areas:

- Emergent response within 24 hours – Section 3.9.1 (A)6
- Time Frames for service authorization determination Section 3.6.1.5.1
- Consider implementing in response time to families and maintenance of MIS.

Thank you again for your continued dedication and commitment to serving children and youth with special needs in New Jersey. If you have questions or would like to discuss this further, please do not hesitate to contact us at newjerseyfspc@gmail.com, or Kyoko Coco, our Statewide coordinator, Kyoko.Coco@njcdd.org, 609-341-3112.

Respectfully submitted,

/s/

/s/

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