



June 15, 2021

The SPAN Parent Advocacy Network (SPAN), New Jersey's Parent Training and Information Center, Family to Family Health Information Center, Federation of Families for Children's Mental Health State Organization, and Parent to Parent USA Affiliate, appreciates the opportunity to provide these comments on New Jersey's Children's System of Care. Two decades ago, SPAN helped spearhead the advocacy that led to the development of the first statewide children's system of care in the country, providing family support and care management organizations and mobile response in every county. We are committed to ensuring that the Children's System of Care for both children with mental health challenges and children with intellectual and developmental disabilities (I/DD) meets the needs of our state's children and families. SPAN continues to strongly support the existence of the CSOC including the network of Family Support and Care Management Organizations and mobile response. We appreciate the opportunity for parent input via the PerformCare Family Leader Workgroup, on which SPAN participates.

Some of our key concerns include:

- The application process is difficult/onerous on both the mental health (MH) and I/DD side. Some parents have reported technology issues with the online application process, with the system timing out in the middle of the application and problems with applying from Mac computers
- Assistance is often needed to help families navigate the system including with applications and appeals (families are seemingly unaware of the appeals process); the information/report demands are time consuming and difficult to satisfy
- The requalification process is a medical qualifying model that is inappropriate for people who will have lifelong developmental disabilities
- There is a need for greater expertise in I/DD for professionals supporting youth with I/DD, for example, capacity to serve families whose children have co-morbid disabilities
- There is significant confusion about transition from services coordinated via PerformCare to services under the Division of Developmental Disabilities for children with I/DD, while children with mental health challenges seem to transition to nowhere
- It is difficult to access ABA services, and there is network inadequacy/lack of many services including appropriate behavior supports and mental health services for children with I/DD
- There are wait lists for respite services, one of the most important services for families
- There are staffing shortages across the board, including insufficient 1-to-1 aides for summer camp programs
- Families are often unaware of available supports, especially DDD
- Requests for increases in supports for mental health issues are often denied (e.g., intensive in-home services)
- Too often, schools still call the police rather than mobile response (with parental consent) to de-escalate. Further, there is no access to mobile response once a family is receiving PerformCare services; families are directed to call law enforcement if the "emergency plan" is not successful
- There is a greater needed for more interaction between the NJ Department of Education, the CSOC, local school districts, families and family support organizations
- There are still concerns with the system reporting families to DCP&P for "noncompliance"
- Family support services are not as robust or available as when delivered under DDD
- There is a need for trained surrogate parents when youth with I/DD are involved with DCP&P
- Children's System of Care staff need more information about IEPs and what their role is at IEP meetings
- There is still a need for services for children under 5 and ages 18-21
- Disparities in access still remain including based on race, ethnicity, and immigrant status.

SPAN looks forward to continued collaboration with the New Jersey State Legislature and the New Jersey Department of Children and Families so that all children with mental health challenges and/or intellectual or developmental disabilities and their families receive the support they need. Please feel free to contact Peg Kinsell at pkinsell@spanadvocacy.org with any questions or for additional discussion.

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