



January 31, 2019

Division of Medical Assistance and Health Services  
Office of Legal & Regulatory Affairs  
Attention: Margaret Rose  
P. O. Box 712, Mail Code #26  
Trenton, NJ 08625-0712

Re: EPSDT Autism Benefit

Dear Ms. Rose,

The SPAN Parent Advocacy Network (SPAN) appreciates the opportunity to submit comments regarding New Jersey's Medicaid State Plan Amendment to increase the autism benefit for EPSDT eligible individuals. SPAN has extensive experience working with families across the state of New Jersey, with a foremost commitment to children with the greatest need due to disability/special healthcare needs, poverty, race/ethnicity, /immigrant status, language, gender, geography, or other special circumstances. We have provided information and support to thousands of families of children with Autism Spectrum Disorders (ASD) and were pleased to be represented on the state team that developed this proposed plan. 30% of our staff are diverse (Caucasian, African-American, Latina, Asian, and South Asian) parents of children with ASD and so have direct experience with New Jersey's current systems and services relating to ASD.

### **Vision**

SPAN endorses and is committed to the vision to:

- Ensure a family and youth-driven approach to services
- Provide an integrated approach to care and expand trauma-competent care
- Ensure timely access to appropriate services and build capacity of providers to serve children with ASD
- Expand specialty services statewide

We would also add to this vision the commitment to provide culturally and linguistically-competent/sensitive/appropriate care for NJ's very diverse population. From our direct experience, we know that there are currently many barriers to identification, evaluation, eligibility, and access to needed supports and services for children of color, immigrant and migrant children, children in families speaking languages other than English, and low-income families, resulting in inequities in outcomes for these children.

## **Plan Components**

SPAN strongly supports the expansion of the autism benefit, including access to an individually planned and coordinated set of services with parent/caregiver/youth choice in the development of the plan of care and focus on maximizing the quality of life for children, youth and young adults with ASD. Providing families with the opportunity to choose services that meet their needs will lead to improved outcomes.

Autism is a spectrum disorder that requires a spectrum of approaches to care. We fully support the State Plan Amendment to expand service options to include evidence-based/informed/supported and/or promising effective developmental and relationship-based approaches and are strongly opposed to limiting services to only ABA based programming and treatments. ABA services are not right for every family; it is important that the plan cover a much wider array of services. Furthermore, ABA techniques often include the use of aversives and restraints, practices that are harmful, and sometimes life-threatening, to children, and are vehemently opposed by SPAN. SPAN particularly wants to recognize the importance of including services aimed at community inclusion, as our state continues to overly segregate children with ASD in out-of-district placements and institutional living settings, to a far greater degree than the national average and many other states. We know from our own children and many families that we have supported that accessing inclusive education and community living is challenging, but when achieved, has many positive benefits for the individual with ASD and their family.

As an organization with over 30 years of providing peer-to-peer support to families of children with disabilities/special healthcare needs, including ASD, and as the federally designated Parent Training and Information Center (PTI) (providing support to families of infants, toddlers, children, youth and young adults with disabilities including ASD) and Family to Family Health Information Center (F2F) (providing support to families of children with special healthcare needs, including ASD, from birth to age 26), SPAN strongly supports the provision of the plan that calls for availability of peer-to-peer supports. SPAN also houses NJ Statewide Parent to Parent (P2P), which matches parents of children with special needs including ASD to trained Support Parents for emotional support and information on resources. We are the NJ State Affiliate for Family Voices (FV) and for Parent to Parent USA, and a chapter of the National Federation of Families for Children's Mental Health. We have the longest history and greatest amount of experience in providing culturally-appropriate and capacity-building peer-to-peer support in our state. (Our PTI, F2F, FV, and P2P Directors have children with ASD).

Two components of the plan that SPAN also strongly supports are 1) expanding services to provide care for individuals aged 14-21; and 2) providing a multidisciplinary array of services delivered in home/out of home, including clinical and community based settings. These provisions support the child/youth's functional development and his/her inclusion in their own community by increasing opportunities to improve and generalize skills, build relationships, and create community connections and natural supports.

The state is to be commended for recognizing the devastating impact of trauma on children and their families and SPAN supports expanding the use of trauma informed practices in care and service delivery. Services that are trauma- and developmentally-informed and reflect a holistic and integrated approach are likely to yield the best outcomes for this diverse population. As noted above in the comments on the Vision, SPAN strongly urges the inclusion of language in the vision and throughout the plan regarding provision of culturally and linguistically-competent/appropriate services. New Jersey is very diverse state – one of the most diverse states in the nation – and services from screening to evaluation, diagnosis, and planning and implementation of services and supports cannot be one-size-fits-all but rather must be tailored to meet the diverse cultural expectations and beliefs and language needs of all families in our state. As an organization with staff representing a vast array of cultures and languages, SPAN has significant experience and expertise in working with families from diverse cultures and languages and helping them access the tailored services and supports they need.

New Jersey continues to have one of the highest rates of autism – and one of the most segregated approaches to serving individuals with ASD - in the country. These are urgently needed services and supports that can make a tremendous difference in the lives of our children and youth living with autism, maximizing their development across all the life domains, increasing the potential for inclusive and meaningful lives, and the resilience and health of their families.

In closing, SPAN would like to recommend that future efforts focus on expanding this benefit to families of children with other developmental disabilities in our state. This would be in the same vein as the 2009 Autism and Other Developmental Disabilities (DDC) Insurance mandate; New Jersey was the first and continues to be the only state where this health insurance mandate covers not only children with ASD but also other DDs. Families of children with developmental disabilities other than autism would benefit from the services proposed in this plan. Further, given the racial disparities in children identified with ASD vs cognitive/intellectual disabilities, narrowing eligibility to children with ASD only will contribute to racial inequities in access to these desperately needed services for families whose children are eligible for EPSDT.



Thank you for your consideration of our comments. Please feel free to contact us if you would like any additional information.

Sincerely,

*Diana MTK Austin*

Executive Co-Director