STATE OF NEW YORK

9868

IN ASSEMBLY

April 24, 2024

Introduced by M. of A. SANTABARBARA -- read once and referred to the Committee on Governmental Operations

AN ACT to amend the executive law, in relation to creating the New York autism spectrum disorders treatment, training and research council and providing for the powers and duties of the council

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Intent. The legislature hereby finds and declares that autism spectrum disorders, hereinafter ASDs, currently affect approximately one in 110 children and are considered to be an "urgent public health concern" by the Centers for Disease Control and Prevention.

The legislature further finds that New York state has not responded sufficiently to this crisis. In its 2010 report, the New York state Interagency Task Force on Autism, hereinafter Task Force, identified five primary needs of the growing population of New York citizens affected by ASDs: coordination of state services, early identification, lifelong service delivery, increased dissemination of information, and coordination of research efforts. First, as a collaborative effort of 11 independent state agencies that each serve individuals impacted by ASDs, the Task Force itself exemplifies the need for coordination of research, treatment and training responsibilities. Second, while the Task Force determined that early identification and intervention were crucial to minimizing the symptoms and impact of ASDs, it reported that only eight percent of pediatricians routinely screen for ASDs and approximately 30 percent of children with ASDs do not receive the early intervention services provided by the New York State Department of Health. Third, recognizing that the thousands of children diagnosed with ASDs will soon age out of the state's educational system, the Task Force noted a dearth of post-secondary training and transitional services. Fourth, the Task Force determined that individuals and families affected by ASDs would benefit from a centralized clearinghouse of relevant information, and called for the provision of user-friendly access to such information. Finally, the Task Force reported that collaboratively determining the direction of future ASD research would best utilize available public and private funding.

The legislature therefore declares that there is a need to expand treatment, training and research with regard to ASDs -- including the

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

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enhancement of efforts to improve access to, and the efficacy of, needed services, support and treatment.

§ 2. Short title. This act shall be known, and may be cited, as the "New York autism spectrum disorders treatment, training and research act".

§ 3. The executive law is amended by adding a new article 41-A to read as follows:

ARTICLE 41-A

NEW YORK AUTISM SPECTRUM DISORDERS TREATMENT, TRAINING AND RESEARCH COUNCIL

Section 908. Definitions.

908-a. New York autism spectrum disorders treatment, training and research council; purpose and organization.

908-b. Functions, powers and duties of the council.

§ 908. Definitions. When used in this article:

1. "autism spectrum disorder" or "ASD" means a neurobiological condition that includes autism, Asperger syndrome, Rett's syndrome, or pervasive developmental disorder;

2. "family" means the parent or legal guardian of an individual diagnosed with an autism spectrum disorder; and

3. "patient" means an individual diagnosed with an autism spectrum disorder.

§ 908-a. New York autism spectrum disorders treatment, training and research council; purpose and organization. 1. There shall be within the executive department the New York autism spectrum disorders treatment, training and research council, hereinafter council, whose purposes shall be to:

(a) develop a coordinated New York state autism spectrum disorders treatment, training and research policy and plan, hereinafter state policy and plan, with respect to the provision of services to patients and their families;

(b) review state agency initiatives for their consistency with the state policy and plan;

(c) provide a continuing forum for discussion related to the development and implementation of the state policy and plan; and

(d) take the steps enumerated herein to expand and coordinate treatment, training and research.

2. The council shall be comprised of twenty-eight members as follows:

(a) the commissioner of the department of health, the commissioner of the department of labor, the commissioner of the office of children and family services, the commissioner of education, the commissioner of the office of mental health, the commissioner of the office for people with developmental disabilities, the commissioner of the office of temporary and disability assistance, the superintendent of financial services, the chancellor of the state university of New York, the chancellor of the city university of New York, the chair of the council on children and families, the chair of the commission on quality of care and advocacy for persons with disabilities, and the executive director of the disabilities planning council, all of whom shall serve ex officio and who may designate representatives to act on their behalf;

(b) seven members appointed by the governor, who shall possess expertise in ASDs. At least two appointees shall represent not-for-profit entities with the primary purpose of providing access to education, information and/or services related to the care of patients; and

(c) eight members appointed by the governor on the recommendation of the legislative leaders as follows:

(1) the temporary president of the senate and the speaker of the assembly shall each recommend three members to the council. The temporary president of the senate and the speaker of the assembly shall each recommend at least one clinical or research expert in the field of ASDs and at least one family member of a patient; and

(2) the minority leader of the senate and the minority leader of the assembly shall each recommend one member to the council.

3. Vacancies in the membership of the council shall be filled in the manner provided for original appointments.

4. The commissioner of the department of health and the commissioner of the office for people with developmental disabilities shall serve, ex officio, as co-chairs of the council. Administrative duties of the council shall be the responsibility of, and executed by, the department of health and the office for people with developmental disabilities pursuant to an agreement effected by the co-chairs.

5. Members of the council shall receive no compensation for their services but shall be reimbursed for necessary expenses.

6. The council shall meet quarterly, or more frequently if its business shall require, provided that the community forums required pursuant to section nine hundred eight-b of this article shall constitute a formal meeting of the council.

§ 908-b. Functions, powers and duties of the council. 1. Not later than one year after the effective date of this article, the council shall conduct community forums to gain input from patients, family members, service providers, expert researchers and other interested parties concerning the development of the state policy and plan required by this section. The council shall then conduct community forums every five years, or more frequently as the council shall determine. Community forums shall be conducted in or around Albany, Binghamton, Buffalo, Long Island, New York City, Northern Metropolitan New York, Plattsburgh, Potsdam, Poughkeepsie, Rochester, Syracuse, and other areas as the council shall determine.

2. The council shall provide the initial report of the state policy and plan required by this section to the governor and the legislature on or before February first, two thousand twenty-five, and shall provide an update of such policy and plan by February first of every year thereafter. The state policy and plan shall include comprehensive information, findings and recommendations concerning, but not limited to, the following:

(a) coordination of services, including: coordinating state services and providing case management; clarifying and streamlining eligibility and intake processes for state service systems; addressing the needs of patients who fail to meet eligibility criteria of state agencies; and uniting public and private agencies in a manner that will best serve patients and their families. In assessing the strengths and gaps in services for patients and their families, the state policy and plan shall include evaluations and recommendations by region;

(b) early identification and intervention, including: standardizing ASD screening practices; training educators, medical professionals and other service providers to recognize and treat ASDs; and promoting early childhood screening by primary care physicians;

(c) lifelong service delivery, including: promoting access to evidence-based services for patients of all ages; establishing treatment guidelines and training programs for caregivers; providing residential supports to adult patients; and implementing employment training and post-school transitional services;

(d) family support, including: expanding respite care options and implementing other means to reduce strain on families;

(e) increased dissemination of information, including: increasing ASD awareness programs; distributing best practices to educators, medical professionals and other service providers; continuing the Task Force's efforts to create a centralized hub of information on ASDs through the launch of an online initiative for Adults and Children on The Spectrum (New York ACTS); and enhancing support for patients and families in non-English speaking communities;

(f) coordinated research, including: utilizing available research funds in the most effective and efficient manner; translating results into improved treatment practices; distributing results to educators, medical professionals and other service providers; and uniting ASD researchers in seeking to achieve a better understanding of ASDs;

(g) financing training, treatment and research in the state, including: making financing more efficient and effective; strengthening family services and supports; providing a seamless spectrum of services irrespective of agency jurisdiction; identifying existing and potential sources of funding; and partnering with private individuals, foundations and other entities; and

(h) a statistical analysis of data concerning the prevalence of autism in New York state, both statewide and by region; a listing of available and proposed programs, and their availability by region; a listing of available and proposed expenditures, and their availability by region; a listing of financial resources available for the provision of services to patients and their families; and such other information as the council shall deem relevant.

3. Except where otherwise prohibited by state statute or by federal law, rule or requirement, the plan shall be binding upon member state agencies, which shall promulgate regulations and take such other actions required to effectuate the state policy and plan.

4. The council shall select and designate regional New York Centers on Autism and Related Disabilities, hereinafter NYCARD facilities, for the purpose of identifying, disseminating, and assisting in the implementation of evidence-based practices to serve patients and their families.

(a) The council shall establish criteria for the selection and designation of NYCARD facilities, which shall include an assessment of applicant facilities:

(1) participation in training teachers, parents and professionals;

(2) level of non-state financial assistance available to support operations;

(3) understanding of program goals and objectives articulated by the council;

(4) proposed geographical area to be served;

(5) proposed work plan and staff expertise;

(6) relationship with entities or communities to be served, evidenced by such factors as representation on boards of directors or advisory committees; and

(7) such other factors as the council shall determine.

(b) The council shall develop a request for proposals, a request for qualifications, or a request for expressions of interest as it deems appropriate; and it shall accept applications in response for designation as a NYCARD facility from not-for-profit, academic and research entities in the state. Within eighteen months after the effective date of this article the council shall:

(1) designate as NYCARD facilities: federal Studies to Advance Autism Research and Treatment (STAART) Network programs located within the state, the Cody Center for Autism and Developmental Disabilities at Stony Brook University, and the Center for Autism and Related Disabilities at the University at Albany;

(2) expand current NYCARD facilities located in or around Albany, Buffalo, New York City, Northern Metropolitan New York and Rochester; and

(3) create one or more NYCARD facilities in or around Binghamton, Plattsburgh, Potsdam, Poughkeepsie, Syracuse and such other areas as the council shall determine.

(c) NYCARD facilities shall provide training, referral and information for parents, educators, medical professionals and other service providers, including:

(1) information and referral;

(2) education and training;

(3) technical assistance and consultation;

(4) provision of, or referral to, family support groups;

(5) dissemination of evidence-based models of practice for effective service delivery; and

(6) such other services as the council shall require.

(d) Where feasible, NYCARD facilities shall also provide treatment-based services including, but not limited to, case consultation and clinical services.

(e) The council is hereby authorized to contract for services with designated NYCARD facilities pursuant to this subdivision and to provide grants pursuant to such contracts within amounts designated specifically therefore. The council may act through one or more member state agencies, which it shall designate by majority vote, for administration of such contracts and grants. Insofar as possible, where provision of such services is paid for, in whole or in part, through a contract with a state agency, the cost charged to recipients shall be reduced pro rata. Contracts with NYCARD facilities shall vary depending on the services to be provided, and any such contract shall require that funding provided by, through or pursuant to this subdivision, not be used to offset existing expenditures for the same or similar programs.

5. NYCARD facilities, as well as organizations receiving federal or non-state grant funds for research, may receive grants pursuant to this subdivision for research within amounts designated specifically therefore. The council is hereby authorized to administer such grants and may act through one or more member state agencies which it shall designate by majority vote. Such grants may allow for the enhancement of activities funded from such non-state sources that are already being undertaken by such organizations, including: the continuation of ongoing research; the provision of technical information; guidance for practitioners on ASD care strategies, therapies, medications and other related matters; collaborations with practitioners, schools and networks; and other activities the council deems appropriate. Such grants may be used for any purpose in furtherance of such activities including, without limitation, the purchase of equipment and supplies, payment of salaries, or other activities and purposes as approved by the council.

§ 4. This act shall take effect immediately.