

AMENDED IN ASSEMBLY JUNE 5, 2008

AMENDED IN ASSEMBLY MAY 22, 2008

AMENDED IN ASSEMBLY APRIL 7, 2008

AMENDED IN SENATE MAY 2, 2007

SENATE BILL

No. 527

Introduced by Senator Steinberg

February 22, 2007

An act to add and repeal Article 9 (commencing with Section 4699) of Chapter 6 of Division 4.5 of the Welfare and Institutions Code, relating to autism.

LEGISLATIVE COUNSEL'S DIGEST

SB 527, as amended, Steinberg. Autism Spectrum Disorders: screening.

Existing law, the Lanterman Developmental Disabilities Services Act, requires the State Department of Developmental Services to contract with regional centers for the provision of various services and ~~support~~ *supports* to persons with developmental disabilities, including Autism Spectrum Disorders (ASD).

Existing law, the California Early Start Intervention Services Act, commonly known as the Early Start program, provides various early intervention services for infants and toddlers who have disabilities or who are at risk of having disabilities to enhance their development and to minimize the potential for developmental delays.

This bill would require the State Department of Developmental Services to partner with at least one regional center to implement a 2-year Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program in at least 3 counties *in key geographic areas*.

The pilot program would establish best practices for early screening, diagnosis, referral, and treatment for children with ASD. The bill would also require the department to establish an advisory committee of stakeholders to assist in coordinating the pilot program.

The bill would require the department and the advisory committee, no later than July 1, 2011, to report to the Legislature and the Governor on the pilot program. The bill would establish the Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program Fund in the State Treasury, to be used by the department, upon appropriation by the Legislature, for purposes of this pilot program. The department would be required to apply to the California Children and Families Commission for funding for the pilot program. The pilot program would only be established after that funding, or funding from other sources, excluding General Fund moneys, was obtained. This bill would make its provisions inoperative on July 1, 2011, and repeal them on January 1, 2012.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: no.

The people of the State of California do enact as follows:

- 1 SECTION 1. The Legislature finds and declares the following:
- 2 (a) The diagnosis of Autistic Disorder, Asperger's Disorder,
- 3 and Pervasive Developmental Disorder Not Otherwise Specified
- 4 all fall under the clinical umbrella term Autism Spectrum Disorders
- 5 (ASD).
- 6 (b) The number of children diagnosed with ASD has grown
- 7 dramatically in recent years and is a serious public health crisis
- 8 that must be addressed. According to the federal Centers for
- 9 Disease Control and Prevention, ASD can now be diagnosed in
- 10 one of every 150 children and can occur in all ethnic, racial, and
- 11 socioeconomic groups.
- 12 (c) Autism Spectrum Disorders are complex neurological
- 13 developmental disorders with onset in early childhood that result
- 14 in substantial impairment in social interaction and communication
- 15 and in the presence of unusual behaviors and interests.
- 16 (d) Recent reports and studies have called attention to significant
- 17 gaps in programs and services for individuals with ASD. Late
- 18 identification and referral for intervention of young children with
- 19 ASD, insufficient preparation and reimbursement of health care

1 professionals, and inadequate collaboration between medical,
2 home, and other systems of care that are important in
3 comprehensive intervention are just a few challenges facing
4 children with ASD and their families.

5 (e) While it is now accepted and supported by research that
6 early screening, diagnosis, and intervention, as well as timely
7 access to services, can improve outcomes and help children with
8 ASD function at higher levels, significant barriers exist to achieving
9 these goals.

10 SEC. 2. Article 9 (commencing with Section 4699) is added
11 to Chapter 6 of Division 4.5 of the Welfare and Institutions Code,
12 to read:

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14 Article 9. The Autism Spectrum Disorders Early Screening,
15 Intervention, and Treatment Pilot Program

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17 4699. (a) As used in this article, “ASD” means Autism
18 Spectrum Disorders.

19 (b) The State Department of Developmental Services shall
20 partner with one or more regional centers to implement a two-year
21 pilot program in *at least three counties* in key geographic areas
22 around the state that will do the following:

23 (1) Identify solutions to significantly improve the quality of
24 health care for children between birth and five years of age with
25 ASD and their families, with particular attention paid to increasing
26 early developmental screening and improving coordination of
27 referral, diagnostic, and treatment services.

28 (2) Develop a comprehensive model of best practices for early
29 identification of children with ASD or other developmental delays
30 and effective referral and coordinated followup care, focusing
31 particularly on culturally, linguistically, and geographically diverse
32 or underserved populations.

33 4699.1. (a) The department shall work with the advisory
34 committee established pursuant to Section 4699.2, as well as local
35 volunteers, including, but not limited to, regional center staff,
36 health care professionals, local education agency and school district
37 staff, and representatives from public and private health insurance
38 companies in the selected counties to achieve the following goals:

39 (1) Use innovative methods to increase early screening for ASD,
40 including the use of parent-completed screening tools, more

1 screening in community settings such as child care, schools, and
2 clinics, and the use of Web-based tools and those that are
3 compatible with electronic medical records.

4 (2) Improve communication between physicians and families,
5 especially when discussing the implications of developmental
6 screening test results, with particular focus on mitigating negative
7 consequences of widespread developmental screening, such as
8 increased parental anxiety or the impact of false positives on
9 interaction with the child while the family awaits diagnosis.

10 (3) Improve collaboration and communication among medical
11 practitioners and local regional centers, Early Start, and local
12 educational systems for referral protocols and procedures for
13 children with positive screens that include feedback to local health
14 care professionals to ensure appropriate medical diagnosis.

15 (4) Use of telehealth and telemedicine strategies for professional
16 development, outreach, and training to primary care physicians,
17 residents in pediatrics and family practice, and medical students,
18 as well as for clinical consultation and to improve access to care
19 in rural sites.

20 (5) Use of adequate payment and reimbursement strategies that
21 will facilitate and incentivize routine screening and facilitate
22 collaborative, coordinated, ongoing care to families within the
23 context of a medical home.

24 (6) Use of incentives for continuing medical education and other
25 professional training and development and practice improvement
26 to assist physician offices with implementation of universal early
27 development screening, including, but not limited to, selecting,
28 obtaining, and utilizing appropriate and validated screening tools
29 and increasing knowledge of referral protocols and treatment
30 options.

31 (7) Increase public awareness about ASD and the fact that early
32 diagnosis and intervention can improve outcomes and increase
33 function in children.

34 (b) The department and the advisory committee may partner
35 with existing public, private, state, or national initiatives to share
36 information and to avoid duplication of efforts and shall build upon
37 the work and recommendations in recent reports and published
38 models.

39 (c) The Legislature recognizes that the regional center system
40 serves individuals who are deemed eligible pursuant to subdivision

1 (a) of Section 95014 of the Government Code and subdivisions
2 (a) and (l) of Section 4512. Nothing in this article is intended to
3 change existing eligibility requirements for receiving regional
4 center services.

5 4699.2. (a) The department shall establish an advisory
6 committee of stakeholders to assist in coordinating the pilot
7 program. The committee shall meet at least once in person, but
8 shall conduct as much business as possible via conference call and
9 electronic means.

10 (b) The committee shall be composed of representatives from
11 each of the following entities, as well as other interested
12 stakeholders that the department deems necessary:

- 13 (1) State Department of Education.
- 14 (2) State Department of Public Health.
- 15 (3) State Department of Health Care Services.
- 16 (4) State Department of Mental Health.
- 17 (5) Department of Managed Health Care.
- 18 (6) University Centers for Excellence in Developmental
19 Disabilities.
- 20 (7) State Council on Developmental Disabilities.
- 21 (8) Association of Regional Center Agencies.
- 22 ~~(9) UC Davis Center for Health and Technology.~~
- 23 (9) *The University of California.*
- 24 (10) American Academy of Pediatrics.
- 25 (11) California Academy of Family Physicians.

26 (c) There shall be no compensation for the advisory committee
27 except for reimbursement for expenses incurred in the conduct of
28 committee business.

29 4699.3. (a) No later than July 1, 2011, the department, working
30 with the advisory committee, shall provide to the Legislature and
31 the Governor a report on the pilot program. The report shall make
32 recommendations for legislative, regulatory, or fiscal initiatives
33 that would further the goal of early identification and treatment of
34 ASD and other developmental delays.

35 (b) The report shall specifically address all of the following:

- 36 (1) The change in referral numbers and patterns from baseline
37 historical trends after training *in*, and implementation of, screening,
38 referral, and assessment protocols.
- 39 (2) The planning and resource allocation required at the state
40 and federal levels to build capacity in, and ensure access to, the

1 regional center system and Early Start programs to prepare for the
 2 influx of autistic children and families that will result from routine
 3 screening, such as achieving reasonable wait times after a family
 4 has been referred for assessment.

5 (3) Accessibility and diagnostic evaluation and intervention
 6 resources for children identified with ASD.

7 (4) The fiscal impact on health care professionals and regional
 8 centers of increased screenings and referrals.

9 (5) Changes in practice patterns for participating physicians,
 10 including residents establishing new practices, and other health
 11 care professionals.

12 (6) The effectiveness of physicians’ developmental monitoring
 13 and screening efforts over time, as policies to encourage
 14 developmental screening are implemented.

15 (7) Cost-effectiveness of routine early screening, referral, and
 16 intervention conducted in a coordinated fashion using the medical
 17 home model.

18 (8) The impact on families in an environment of universal,
 19 widespread developmental screening, including the impact of false
 20 positives on parent-child interaction.

21 (9) Other factors as the department and the advisory committee
 22 deem appropriate.

23 (c) The preparation of the report shall be funded through federal,
 24 state, or private funds secured with the help of the advisory
 25 committee. No state general funds shall be used to prepare the
 26 report.

27 4699.4. (a) The Autism Spectrum Disorders Early Screening,
 28 Intervention, and Treatment Pilot Program Fund is hereby created
 29 in the State Treasury. The department shall deposit any moneys
 30 received from the state, federal government, or from private
 31 donations into the fund, to be used by the department, upon
 32 appropriation by the Legislature, for the pilot program.
 33 Notwithstanding Section 16305.7 of the Government Code, interest
 34 and dividends on moneys in the fund shall accrue to the fund.

35 (b) No state general funds shall be used to fund the pilot
 36 program. The department shall apply to the California Children
 37 and Families Commission for funding to cover the pilot program.
 38 The pilot program shall be established only after the department
 39 has applied to, and obtained funds from, the California Children
 40 and Families Commission or other sources.

1 4699.5. This article shall become inoperative on July 1, 2011,
2 and, as of January 1, 2012, is repealed, unless a later enacted
3 statute, that is enacted before January 1, 2012, deletes or extends
4 the dates on which it becomes inoperative and is repealed.

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