

BILL ANALYSIS

Senate Research Center

S.B. 1612
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Health & Human Services
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Enrolled

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

Velocardiofacial syndrome (VCFS) is caused by a microdeletion of the 22nd chromosome and is the second most common genetic abnormality after Down syndrome, occurring in one in 2,000 births. There are more than 180 features associated with the deletion but the most commonly associated symptoms are: conotruncal congenital heart disease; anatomic and/or neuromuscular abnormalities of the palate; recognizable, typical facial appearance; immune system disorders; and speech, learning, and psychiatric problems. Significant published scientific literature exists regarding symptoms associated with VCFS and appropriate treatments and educational and therapeutic supports.

Despite its relatively frequent occurrence and several commonly associated symptoms, VCFS is largely undiagnosed and members of the medical, educational, public sector, and disability communities are generally unfamiliar with the condition. As a result, children and adults with VCFS are not receiving appropriate medical, therapeutic, or educational treatment and supports for associated problems. In particular, children and adults with VCFS in Texas suffer with generally treatable but undiagnosed heart and immune system problems, calcium and magnesium deficits, cleft palate-related complications, severe articulation and speech delays, and psychiatric problems, among other things.

Due to common speech and developmental delays, even undiagnosed children with VCFS are often qualified for the Early Childcare Intervention (ECI) services. However, due to an unfamiliarity with VCFS among ECI providers, these children are generally not receiving information to therapy related to the disorder.

Current law authorizes ECI services to be provided to children zero to three years of age with significant developmental delays, including children with VCFS.

S.B. 1612 amends current law relating to the provision of information by health and human services agencies to assist children with velocardiofacial syndrome.

RULEMAKING AUTHORITY

Rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 1 (Section 117.076, Human Resources Code) of this bill.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends Subchapter D, Chapter 117, Human Resources Code, by adding Section 117.076, as follows:

Sec. 117.076. INFORMATION REGARDING VELOCARDIOFACIAL SYNDROME.

(a) Requires the Health and Human Services Commission (HHSC) to ensure that each health and human services agency that provides intervention services to young children is provided with information developed by HHSC regarding velocardiofacial syndrome.

(b) Requires each health and human services agency (agency) described by Subsection (a) to provide the information regarding velocardiofacial syndrome to appropriate health care coordinators and therapists and to parents of a child who is known by the agency to have at least two of the following conditions:

hypotonicity; communication delay; articulation disorder; resonance disorder; nasal regurgitation during feeding as an infant with no history of a cleft palate; recurrent ear infections as well as diagnosis of cardiac anomaly, feeding disorder, cleft palate, or submucosal cleft palate; or fine motor or gross motor skills delay.

(c) Requires HHSC to develop the information required under Subsection (a) using medically accurate, peer-reviewed literature. Requires that the information include an explanation of velocardiofacial syndrome symptoms, diagnosis, and treatment options; information on relevant state agency and nonprofit resources, parent support groups, and available Medicaid waiver programs; and a recommendation for follow-up with a health care provider for evaluation of the underlying etiology and an explanation that the existence of any of the conditions listed in Subsection (b) will not necessarily result in a diagnosis of velocardiofacial syndrome.

(d) Authorizes the executive commissioner of HHSC to adopt rules as necessary to implement this section.

SECTION 2. Effective date: September 1, 2009.