

BILL ANALYSIS

C.S.S.B. 1612
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Human Services
Committee Report (Substituted)

BACKGROUND AND PURPOSE

Velocardiofacial syndrome (VCFS) is caused by a microdeletion of the 22nd chromosome and is the second most common genetic abnormality after Down's syndrome, occurring in one in 2,000 births. There are more than 180 conditions associated with the deletion but the most commonly associated symptoms are conotruncal congenital heart disease; anatomic or neuromuscular abnormalities of the palate, or both; recognizable, typical facial appearance; immune system disorders; and speech, learning, and psychiatric problems. Significant published scientific literature exists regarding the 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 support for their 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 deficiencies, cleft palate-related complications, severe articulation and speech delays, and psychiatric problems, among other things. Parents of children with VCFS report that their children are highly empathetic and caring, loving individuals who work hard to contribute to their environments.

Due to common speech and developmental delays, even undiagnosed children with VCFS often qualify for early childhood intervention services. However, due to an unfamiliarity with VCFS among intervention services providers, the parents of these children are generally not receiving information on therapy related to the disorder.

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

C.S.S.B. 1612 sets forth provisions relating to the provision of information by health and human services agencies to assist children with velocardiofacial syndrome.

RULEMAKING AUTHORITY

It is the committee's opinion that rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 1 of this bill.

ANALYSIS

C.S.S.B. 1612 amends the Human Resources Code to require 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. The bill requires each health and human services agency that provides such services 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.S.S.B. 1612 requires HHSC to develop the required information regarding velocardiofacial syndrome using medically accurate, peer-reviewed literature. The bill requires the information to 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 above will not necessarily result in a diagnosis of velocardiofacial syndrome. The bill authorizes the executive commissioner of HHSC to adopt rules as necessary to implement these provisions.

EFFECTIVE DATE

September 1, 2009.

COMPARISON OF ORIGINAL AND SUBSTITUTE

C.S.S.B. 1612 adds a provision not in the original requiring the information regarding velocardiofacial syndrome developed by the Health and Human Services Commission to additionally include 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 by the bill will not necessarily result in a diagnosis of velocardiofacial syndrome.