

HB 2513 -- CHILDREN WITH RARE OR MEDICALLY COMPLEX CONDITIONS

SPONSOR: Byrnes

This bill requires the development, documentation, and maintenance of an individualized care plan for a child with a rare or medically complex condition, to be executed by all health care providers for that child. The care plan must include clear instructions for emergency care and identification of the child's primary specialist responsible for the plan's oversight. The child's providers must review and make any necessary changes to the plan annually, as well as after any hospitalization of the child.

The bill requires hospitals and emergency services providers to maintain logs of their adherence to individualized care plans, protocol deviations, and handoffs between emergency services providers and hospital care teams for children with rare or medically complex conditions. Hospitals and emergency service providers are additionally required to create reporting procedures to provide documentation of any significant protocol deviations within 24 hours to the child's primary specialist and the quality and safety officer designated by the hospital.

The bill requires the Department of Health and Senior Services to audit health care providers for compliance with the provisions of this bill following any receipt of reports of noncompliance, and may order the provider to implement a corrective action plan if violations are determined to have occurred.

This bill requires each health care provider to offer required training on rare diseases for all pediatric health care professionals, and encourages health care providers to maintain a centralized registry of individualized care plans for all children with rare or medically complex conditions that is accessible to authorized health care professionals and emergency services personnel.

The bill prohibits retaliation against a caregiver for advocating for adherence to the individualized care plan or for reporting protocol deviations. Additionally, if systemic failures in implementation of an individualized care plan occur and a poor outcome would have been avoidable, the bill requires hospital leadership to meet with the child's caregiver, upon his or her request, for any review of the individualized care plan.

This bill has a delayed effective date of March 1, 2027.