

Agency Response to the Department of Planning and Budget's Economic Impact
Analysis (EIA) on 12 VAC 5-191
(State Plan for the Children with Special Health Care Needs Program)

Virginia Department of Health (VDH) generally concurs with the Virginia Department of Planning and Budget's (DPB) EIA, except that important details reflecting the complex history of this regulatory action have not been sufficiently detailed.

DPB states that the "Children with Special Health Care Needs Program has already been operating under the proposed version of the rules implemented in phases since the late 1990s". While DPB is correct in acknowledging that program operations have changed, the first program transition actually commenced in 2001. DPB also states that "implementing operational changes without going through the regulatory process and then updating the regulations to reflect what is already implemented in practice is a problematic approach as the agency would be operating contrary to its regulation. The lack of authority to enforce regulatory provisions combined with discrepancies between regulations and procedures followed in practice creates a potential for costly litigation expenses." With this statement DPB fails to acknowledge two key points:

- VDH has been following the established regulatory process to act on this regulation since 1994. Changes over four administrations significantly contributed to the delays experienced in resolving this regulatory action.
- VDH followed model of care changes promoted by the federal government--the primary funding source for the program.

VDH started appropriate regulatory action to repeal 12 VAC 5-190 beginning in 1994. It was not until 2004, ten years later, that it was definitively established by the Office of the Attorney General that this entire regulation must continue to exist in its entirety. VDH has followed regulatory processes to develop and maintain separate regulations for state-mandated services for specific special needs populations. Provision of services to special needs children in the broadest definition is not a state mandate.

Provision of services to children with special health care needs (CSHCN) is neither a federal nor state mandate per se. The state receives federal funds under the Social Security Act (Title V) for maternal and child health services, which does require an annual plan, and stipulates that 30% of funds be spent on CSHCN. Section 32.1-77 of the *Code of Virginia* authorizes, but does not require, the Board of Health to submit a state plan for maternal and child health services. Other more specific programs are mandated by the Code of Virginia to identify and serve children with special health care needs. These include Virginia Newborn Screening Services and Virginia Early Hearing Detection and Intervention Program. These programs are governed by separate regulations.

The history of the regulation for children with special health care needs is complex and involves four administrations with varying opinions of how to handle this matter. In 1994, following Executive Order 15, it was determined that the State Plan for Children's Specialty Services (now known as Children with Special Health Care Needs

Program) did not need to exist as a regulation, but that the plan could be operated using guidance documents. Concerns regarding the rights of persons to demand services and appeal decisions arose, however, and were debated through subsequent administrations. Changes were made to the VDH general eligibility regulations (12 VAC 5 200 et seq.) to address these concerns. VDH continued with regulatory action to repeal the State Plan (Pre-NOIRA and NOIRA) with complete Executive Branch approval up through the Governor's Office. In 1999, however, the Office of the Secretary of Health and Human Resources decided against the repeal of the regulations following advice by the OAG, due to concerns about the annual fee then charged to participants. VDH temporarily withdrew from the regulatory action stage to consider which specific components of the plan needed to exist as a regulation.

During this time period, tremendous changes transpired in the health care system with direct impact on VDH programs. VDH conducted a comprehensive needs assessment of CSHCN in 1999, as mandated by the U.S. Department of Health and Human Services in order to receive federal Title V Maternal and Child Health funds. This assessment conducted by Health Systems Research, Inc. (HSR) revealed that (in 1998):

- Primary care capacity is strong
- Medical specialty capacity is excellent, however significant unmet needs in accessing durable medical equipment, prescription drugs, and/or nutritional supplements persisted.
- Families are generally ill supported by the system as evidenced by a lack of information, advocacy and support services.
- Insurance coverage and benefits are not equitably and consistently available to all CSHCN families.
- Systems of care for CSHCN are not adequately coordinated and integrated.
- Systems designed to serve families with CSHCN do not sufficiently and consistently value the experience and input of family members.

The following recommendations were made by HSR to address unmet needs:

- Organize and convene a State Interagency Public/Private Council for CSHCN
- Strengthen Virginia's Centers of Excellence for CSHCN (to enhance capacity and broaden the role of specialty hospitals for children)
- Establish Regional Resource Centers for CSHCN (to promote development of resource information, advocacy, cross-system referral and coordination, and systems of family support)
- Create a Statewide Family-to-Family Network

The assessment also noted that, with the implementation of the federal State Children's Health Insurance Program under Title XXI, up to 70,000 children in low income families would become insured and have greater access to private health care resources. At the same time, Medicaid enrollees were being transitioned to managed care, which opened up significant networks of primary and specialty health care providers. These changes

effectively reduced the pressure on the VDH program to function as a third party payer or provider of services to those without insurance.

VDH was under federal obligation to consider these findings and develop a state plan for CSHCN to address identified unmet needs. Section 505 of the Title V Social Security Act requires that a statewide needs assessment be conducted every five years and that each fiscal year states submit a plan for meeting the needs identified by the statewide needs assessment. Had VDH not developed a plan to meet the identified needs, the state may have been at risk of having the plan for CSHCN not approved by the federal government, the primary funding source for serving this population.

The State Health Commissioner was notified in 2001 that the old Children's Specialty Services program would be terminated and replaced by a community based system for care coordination, with retention of some funding to pay for needed services (as identified in the needs assessment) for uninsured or underinsured children. This was done to meet the unmet needs identified from the assessment while most efficiently using finite resources. In 2001, Virginia Secretary of Health and Human Resources reversed sentiment expressed in 1999 and approved repeal of the regulation.

Throughout all of the changes made to services for CSHCN, VDH has acted in accordance with federal directives. The original 1935 enactment of the Social Security Act authorized federal grants for "Services for Crippled Children" to extend and improve services for locating crippled children and for providing medical, surgical corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare for this population.

The first services for special needs children involving a partnership between the state and children's specialty medical providers began in the late 1930s between the existing Bureau of Crippled Children (State Department of Health) and the Virginia Orthopaedic Society. In 1939 the two organizations met to restructure the state orthopedic clinics and to recommend that hospitalization for crippled children should be available in Roanoke, Lynchburg and Norfolk. State money totaling \$132,626 was matched by federal funds from Title V of the Social Security Act. The initial regulation governing the program 12 VAC 5-190 was first developed 50 years later in 1987. Seven years later it was decided after mandated review (E.O. 15 in 1994) to start the process to repeal the regulation.

In the midst of these regulatory changes, major changes were also transpiring in health care nationwide. Major changes in philosophy and medical care for special health care needs children, which had occurred over decades since the original 1935 Title V enactment, spurred the federal government to make several major revisions to Title V of the Social Security Act. This federal legislative change was made to enable states to better meet needs of maternal and child populations including "crippled children".

The Consolidated Omnibus Budget Reconciliation Act of 1985 removed the terminology of "crippled children", replacing it with "children with special health care

needs”. This was reflective of the direction being given to states to expand their definitions of special needs children beyond certain diagnoses. Following this change, the Omnibus Budget and Reconciliation Act (OBRA) of 1989 significantly amended Title V of the Social Security Act. It redefined the mission and functions of State CSHCN Programs to:

- “Provide and promote family-centered, community-based, coordinated care (including care coordination services...) for children with special health care needs (42 U.S.C. §701 (a) (1) (D)).
- Care coordination was defined in this legislation as “services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families” (42 U.S.C. §701 (b)(3)).

OBRA ’89 also incorporated by reference the National Health Promotion and Disease Prevention Objectives for the Year 2000 related to children with special health care needs and their families. OBRA ’89 required that the needs assessment be consistent with health status goals and national health objectives, and that states report annually on the extent to which these national health objectives have been met, in order to receive Title V funding. The national health objective (Objective 17.20 Healthy People 2000) related to CSHCN was to “Increase to 50 the number of States that have service systems for children with or at risk of chronic and disabling conditions, as required by Public Law 100-239”. The objective further describes service systems as “organized networks of comprehensive, community-based, coordinated, and family-centered services.”

In addition, the national agenda for children with special health care needs (2000) called for states to carry out legislative responsibilities to develop these community systems and to provide **or** arrange for uncovered services. Studies showed that the federally led shift from lengthy hospitalizations for CSHCN to community based systems of care saved from \$1,200 to \$1,500 per month per child. As noted in 1990 by the former Surgeon General of the United States Public Health Service, the federal government helped states move from a “categorical to non-categorical paradigm of service delivery, from medical to more functional definitions of disability...and from isolated to integrated models of providing services.”

Based on this paradigm shift, all state CSHCN programs are now evaluated by the federal government on six outcomes:

- Medical Home (To assure children have a source of ongoing routine health care)
- Insurance Coverage (To assist children in obtaining and effectively utilizing health insurance)
- Screening (To identify high risk conditions early)
- Organization of Services
- Families’ Roles (To assure that families are involved in all aspects of care and that their opinions are valued)

- Transition to Adulthood (To assure that children with special health care needs are adequately transition to an adult system of care)

Programs are not evaluated on provision of clinical based services governed by specific diagnoses. The old Children's Specialty Services would not efficiently meet the needs of special health care children as identified by the 1999 assessment. The state was required to develop a plan to meet these needs and to be evaluated under newly developed federal definitions and standards.

The new program implemented by VDH since 2000 was designed to satisfy federal expectations, assure continued funding, and meet current needs identified by the 1999 assessment. At each step of the process, VDH made every effort to meet the legislative intent of the program as specified in Title V of the Social Security Act, as well as to operate in accordance with regulatory requirements of the Commonwealth. VDH wants the record to note that the regulatory process was followed with good faith, and that the steps to terminate the prior program were initiated while the action to repeal the State Plan was in process. The description of the program and regulatory changes presented here presents a more accurate picture of what has transpired over the last ten years. At no time did VDH act to expose the state to litigation risks, and failure to act may have jeopardized federal funding.

In addition the EIA indicates that providing care coordination services to all applicants regardless of income could result in resources being taken away from low-income applicants, should the demand exceed resources. DPB suggests VDH develop a plan to prioritize resources if necessary. However, as DPB has noted the Commissioner has the authority to take actions to address this issue if necessary. VDH will consider this recommendation and amend the regulation at a later date, but does not wish to see any further delay of this regulatory action. It should also be noted that VDH does maintain details of acceptable purchases under the Pool of Funds in guidance documents.