



How 3 AAP chapters and Title V are improving the lives of children with special needs

by **Kristy Kennedy** • Correspondent

The secret to success between AAP chapters and state Title V Maternal and Child Health programs for children with special health care needs really is no secret.

Two things are necessary: good communication and collaboration.



Dr. Romano

“There is this synergy between what needs to be done on a state level and what a chapter can do to help that and then vice versa,” said Judith T.

Romano, M.D., FAAP, president of the AAP Ohio Chapter.

“We need each other to leverage state and federal dollars for the benefit of children.”

The Title V Maternal and Child Health Program, part of the Social Security Act, will celebrate its 90th anniversary next year. The program provides block grants supporting a wide range of health programs serving about 44 million women and children each year. At least 30% of funding is earmarked for children with special health care needs.

Dollars specifically go toward programs that ensure access to quality care; reduce infant mortality; increase the number of children receiving health assessments and follow-up services; and implement family-centered, community-based systems of coordinated care for children with special health care needs.

In states like Ohio, Washington and Wisconsin, AAP chapters work with their state Title V directors to identify and address health care needs for children and mothers.

State officials in Ohio, for example, realized it was taking years for some children to be diagnosed with developmental disabilities, which in turn, delayed early intervention, Dr. Romano said. A program was created with the AAP chapter to train 900 doctors across Ohio to offer screening services even in the most rural, poor areas of the state. The program calls for children with special health care needs to have a managing physician, supporting the medical home model. The two groups also have collaborated on a project to improve the delivery of children’s mental health services.

“What the AAP chapter gives the state is the opportunity to develop these programs,” Dr. Romano said. “It’s a really wonderful thing.”



Gregory S. Liptak, M.D., M.P.H., FAAP

The Ohio Chapter has made participation in Title V programs particularly attractive by developing ways for members to meet Maintenance of Certification requirements. “Ohio has really been a leader in this area,” Dr. Romano said.

“Pediatricians have the chance to get assistance with some of the most difficult problems they face in their practices — children with behavioral and mental health issues. And they have the chance to do quality Maintenance of Certification through their chapter and through their practice.”

In Wisconsin, five regional centers support children with special health care needs through an integrated system. In

some rural areas of the state, access to specialty care is not convenient for children with special needs, said Wisconsin Chapter President James Meyer, M.D., FAAP. With the state and AAP chapter working together, programs have been able to identify children with needs and coordinate their care.

For instance, as part of the Wisconsin Statewide Medical Home Initiative, care has been expedited for children with developmental delays through the creation of a single form that is compliant with the Health Insurance Portability and Accountability Act and Family Educational Rights and Privacy Act. This allows medical professionals and other clinicians working with children with developmental delays to communicate with each other.

Primary care clinicians across the state have received training on how to integrate behavioral health into pediatric primary care. Programs address mental health as well.

“The Wisconsin Chapter has had mental health as a main priority for some time,” Dr. Meyer said. Telemedicine has become popular in some rural parts of Wisconsin, and a state telephone consultation line staffed by child and adolescent psychiatrists has been set up for primary care clinicians.

Meanwhile in Washington state, Title V staff and AAP members share information about issues providers face in their clinics to impact policies that affect children with special needs such as autism or those in Medicaid managed care arrangements. It’s not unusual for



Dr. Meyer

ideas for grants in the planning stages to be bounced off AAP members to see if they will be useful. At the same time, AAP members are responsive to the needs of their patients and have been receptive to programs like universal developmental screening in the state through the Great MINDS (Medical Homes Include Developmental Screening) program.



Dr. Hood

Washington Chapter President Margaret E. Hood, M.D., FAAP, calls the relationship between chapter members and Title V staff an essential cornerstone in state child health care.

All three AAP chapter presidents say another key to success is improving communication with pediatricians and parents in their states.

“One of the things we could do better is to connect Title V with the whole community of pediatricians and increase their knowledge about what resources are available,” Dr. Hood said. “One of the biggest gaps is not knowing what resources are available to them.”

Parental involvement is crucial. Dr. Hood also would like to see parents more involved as team members of the medical home. Beyond that, the chapter presidents also would like to see more done to address the effects of toxic stress and adverse childhood experiences on children and health.

Top 10 things pediatricians should know about Title V

1. The Title V Maternal and Child Health Services block grant is the nation's oldest federal-state partnership focused on assuring the health of women, children and adolescents, including children and youth with special health care needs and their families.
2. Title V programs typically are located within state public health departments. In some states, the program for those with special health care needs is located within a university. To find your Title V program, visit www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx.
3. Title V programs are a resource for pediatricians and patients in areas such as preventive services, screening, care coordination and programs that help youth with special needs transition into adult health care delivery systems.
4. States use their Title V funds to support a range of activities designed to improve the health of children, including those with special needs and their families.
5. Title V program investments support the work of pediatricians and other primary care providers in areas such as medical home, promotion of the *Bright Futures Guidelines* and access to care.
6. Title V programs can pay for health care services not covered by public insurance (e.g., Medicaid) or private insurance (known as the “payer of last resort”). Payment for health care services varies by state.
7. Most state programs pay for support services such as translation, transportation, respite care, family support, case management and care coordination.
8. Title V programs help families access services for their children through programs such as hotlines and application assistance for children who may be eligible for Medicaid or the Children's Health Insurance Program.
9. Title V directors have a strong understanding of children's health needs since they are required to conduct statewide, comprehensive needs assessments. To find your Title V director and Maternal and Child Health leadership, visit <https://mchdata.hrsa.gov/tvisreports/ContactInfo/StateContactSearch.aspx>.
10. AAP chapters are partners for Title V programs, ensuring that the unique needs of children and adolescents are met. To find your AAP chapter, visit www.aap.org/en-us/about-the-aap/chapters-and-districts/Pages/chapters-and-districts.aspx

For more information about Title V programs, visit www.amchp.org/About-TitleV/Documents/Celebrating-the-Legacy.pdf.